TÉCNICO LISBOA

Shared decision making in clinical settings: Developing participatory processes to assist patients and surgeons in the medical encounter

Developing a new method for community-shared decision making.

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Abstract

In a world where access to clinical evidenced based information is easier everyday, shared decision making is increasingly being a topic of discussion. It is understood as a sharing of information between parts to reach an option agreement. Typically, physicians share knowledge and patients expose their thoughts and concerns. There are some actions that would need for the involvement of a community to be effective. This work introduces a new concept: community-shared decision making. Although it is under the frame of SDM it is an unexplored topic.

The medical decision presented is the Human Papillomavirus vaccination in men, the objective of the thesis is to assist the community of patients to communicate among themselves regarding this topic.

When facing a decision where different aspects matter, a multicriteria decision analysis method is required. This method follows a socio-technical approach. The social component aims to capture the points of views of participants, the technical one builds a model to help elicit a decision taking into account all the criteria that matters and at which level.

Male university students were invited to an online 2 round Delphi process. They were presented with the highlights of HPV and vaccine's implications and, later, asked to assess importance of them. The community SDM was given at this point, while presented with the views of the colleagues and having to assess importance again.

The results showed a remarkably low awareness of HPV. The community also presented a high concern for being protected against the infection. For the other implications, a high dispersion of results was obtained, therefore, the medical society could not be informed about male's community decision regarding the vaccine. Future work needs to be done and the medical community needs to raise awareness regarding HPV.

Key words: Welphi, MACBETH, Human Papillomavirus, shared decision making.

Resumo

Num mundo em que o acesso à informação baseada em evidência clínica é todos os dias mais fácil, a tomada de decisões partilhada por médicos e pacientes é cada vez mais um tema em discussão. No entanto, tradicionalmente, os médicos partilham conhecimento e os pacientes expõem os seus pensamentos e preocupações. Existem ainda algumas situações médicas que, para serem efetivas, precisam do envolvimento de toda a comunidade. Embora alinhado com o conceito da tomada de decião partilhada, este trabalho explora um conceito ainda não explorado, o da tomada de decisão partilhada pela comunidade. A decisão médica apresentada é a vacinação para o vírus do papiloma humano (HPV) em homens, e o objetivo da tese é auxiliar a comunidade de pacientes a acomunicarem entre si sobre este tópico.

Quando enfrentamos uma decisão em que diferentes aspetos são importantes, é necessário um método de análise de decisão multicritério. Este método segue uma abordagem sócio-técnica. O componente social tem como objectivo capturar os pontos de vista dos participantes, o componente técnico constrói um modelo para ajudar a obter uma decisão tendo em consideração todos os critérios relevantes para a problemática.

Estudantes universitários masculinos foram convidados para um processo on-line Delphi com duas rondas. Os estudantes foram depois confrontados com os portos mais importantes do HPV e as implicações da vacina e, mais tarde, foram questionados acerca da sua importância. O processo de tomada de decisão em comunidade tem lugar na fase em que os alunos, de forma individual, tomam conhecimento do ponto de vista dos seus pares e são convidados na reconsideração a ponderação anteriormente realizada, podendo resultar desta ponderação uma mudança de opinião no sentido de uma opinião consensual dentro da comunidade.

Os resultados mostraram em primeiro uma notável baixa consciência das implicações do HPV, embora a comunidade estudantil universitária masculina também apresentasse uma grande preocupação paraser protegido contra a infeção. Para as outras implicações (por exemplo, custo, tempo de tratamento), obteve-se uma grande dispersão de resultados, e desta forma, não foi possível informar a comunidade médica com resultados finais acerca da decisão da comunidade universitária masculina em relação à vacina. É necessário realizar trabalho futuro precisa e principalmente promover uma maior consciencialização da comunidade universitária sobre este tema.

Palabras chave: Welphi, MACBETH, Human Papillomavirus, tomada de decisões partilhada.

Resumen

En un mundo donde el acceso a la información de evidencia clínica es cada día más fácil, la toma de decisiones compartida es cada vez más un tema de debate. Se entiende como el compartir información entre partes para llegar a un acuerdo. Típicamente, los médicos comparten conocimiento y los pacientes exponen sus pensamientos y preocupaciones. Hay algunas acciones que, para ser efectivas, necesitarían la implicación de toda la comunidad. Este trabajo introduce un nuevo concepto: la toma de decisiones compartida en comunidad. A pesar de que está bajo el marco de la toma de decisiones, es un tema inexplorado.
La decisión medica presentada es la vacunación del virus del papiloma humano en chicos, el objetivo de la tesis es ayudar al conjunto de pacientes a comunicarse entre ellos.

Al enfrentarse a una decisión donde importan distintos aspectos, se requiere un método de análisis de decisión multicriterio. Este método sigue un enfoque socio técnico. La parte social quiere capturar el punto de vista del participante mientras que la técnica construye un modelo que ayuda a la obtención una decisión teniendo en cuenta los criterios que importan y a qué nivel.

Los universitarios masculinos fueron invitados a un proceso online de Delphi de dos rondas. Se les presentaron los aspectos más destacados de las implicaciones del VPH y la vacuna y, más tarde, se les pidió que evaluaran la importancia de estos. La toma de decisiones compartida en comunidad se dio en este momento, mientras se presentaba la opinión de los compañeros y tenían que evaluar la importancia nuevamente.
Los resultados mostraron una notable baja conciencia del VPH. La comunidad también presentó una gran preocupación por estar protegido contra la infección. Para las otras implicaciones, se obtuvo una alta dispersión de resultados, por lo tanto, la sociedad médica no pudo ser informada sobre la decisión de la comunidad masculina con respecto a la vacuna. Es necesario seguir trabajando en este tema y la comunidad médica necesita concienciar sobre el VPH.

Palabras clave: Welphi, MACBETH, Virus del papiloma humano, toma de decisiones compartida.

Resum

En un món on l'accés a la informació d'evidència clínica és cada dia més fàcil, la presa de decisions compartida és cada vegada més un tema de debat. S'entén com el compartir informació entre parts per arribar a un acord. Típicament, els metges comparteixen coneixement i els pacients exposen els seus pensaments i preocupacions. Hi ha algunes accions que, per ser efectives, necessitarien la implicació de tota la comunitat. Aquest treball introdueix un nou concepte: la presa de decisions compartida en comunitat. Tot i que està sota el marc de la presa de decisions, és un tema inexplorat.
La decisió mèdica presentada és la vacunació del virus del papil·loma humà en nois, l'objectiu de la tesi és ajudar al conjunt de pacients a comunicar-se entre ells.

En enfrontar-se a una decisió on importen diferents aspectes, es requereix un mètode d'anàlisi de decisió multicriteri. Aquest mètode segueix un enfocament soci tècnic. La part social pretén capturar el punt de vista del participant mentre que la tècnica construeix un model que ajuda a l'obtenció d'una decisió tenint en compte els criteris que importen i a quin nivell.

Els universitaris masculins van ser convidats a un procés en línia de Delphi de dues rondes. Se'ls van presentar els aspectes més destacats de les implicacions del VPH i la vacuna i, més tard, se'ls va demanar que avaluessin la importància d'aquests. La presa de decisions compartida en comunitat es va donar en aquest moment, mentre es presentava l'opinió dels companys i havien d'avaluar la importància novament.
Els resultats van mostrar una notable baixa consciència del VPH. La comunitat també va presentar una gran preocupació per estar protegit contra la infecció. Per a les altres implicacions, es va obtenir una alta dispersió de resultats, per tant, la societat mèdica no va poder ser informada sobre la decisió de la comunitat masculina pel que fa a la vacuna. Cal seguir treballant en aquest tema i la comunitat mèdica necessita conscienciar sobre el VPH.

Paraules clau: Welphi, MACBETH, virus del papil·loma humà, presa de decisions compartida.

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List of Acronyms

DA Decision Aids

DM Decision Maker

HCP Health Care Provider

HPV Human Papillomavirus

IPDAS International Patient Decision Aid Standards

MACBETH Measuring Attractiveness by a Categorical Based Evaluation Technique

MCDA Multi Criteria Decision Analysis

PDA Patient Decision Aids

SDM Shared Decision Making

1. Introduction

1.1. Motivation

The search of health information is everyday more common. People are more interested, and it is easier to be informed, and therefore to understand symptoms, tent diagnosis, have a say on treatments and inherent prognosis. In this context, shared decision making is increasingly being a topic of discussion about if it should be the norm in the medical encounter.
Nevertheless, a lot can be said in regard to this rendezvous, in order to correctly assess the possible elective options in the health field, two types of experts are needed: the clinicians, which provide technical information on options, outcomes and probabilities; and the patients to adjudicate the value of good and bad outcomes. However, different studies show that clinicians have difficulties in understanding patients' values and patients commonly have unrealistic expectations of the benefits and harms of the treatments and/or options they might face. [1]

Traditionally, "shared decision making" is the procedure by which patients and their respective clinicians, discuss and concur to an agreement about an alternative treatment and/or option. As for patients may be arduous to adequately weight the risk and benefits that an option involves, patient decision aids as well as other communication techniques were developed and are seen as an essential part for shared decision making to happen. [1] There are however medical situations which go beyond the clinician-patient dyad and have effects in the community. A clear example is the individual decision to get vaccinated that will ultimately affect the immunological status of an all community. These are medical situations that ideally should be discussed by individuals as a community, with the results of that discussion being used to inform the clinicians on which strategies should be put in place to promote a given vaccination plan. This topic constituted the primary motivation for this dissertation.
A prominent medical subject being discussed in Portugal at the moment is the inclusion in the national vaccination plan of the vaccine towards Human Papillomavirus (HPV) for males. Since approval of the quadrivalent HPV vaccine for females in 2006 interest in expanding HPV vaccination coverage to males has steadily increased. HPV infected men are at risk of developing HPV related diseases and they increase the risk of infection in women. Vaccinating boys could not only decrease the disease burden in males, but also protect women by interrupting ways of transmission. [2]
Human Papillomavirus (HPV) is the most common sexually transmitted disease among students worldwide. Despite this, studies show how students barely know about the virus and its possible diseases. [3]

The lack of knowledge shown by university students in this important health care problem, and the fact that it constitutes a good case study to explore methods to the applied for enhancing patient community-shared decision making, made the final motivation for this thesis.

1.2. Objectives and methodology

The main objective of this thesis is to explore a new method that can be applied for enhancing patient community-shared decision making. Furthermore, while developing such method this thesis will try to get insights into male university students' beliefs and opinions regarding HPV vaccination that will later inform medical doctors regarding this important medical condition. Considering we are exploring a new approach and there is also a great lack of information regarding the HPV vaccination in male university students, this study can be considered exploratory. It will collect information regarding the applicability of the method being developed and make a first survey at the male university students' beliefs and values, that will later set the basis for future studies.

The new approach follows a socio-technical approach since it involves a technical component, as the modelling of male' views in a multicriteria model, and a social component to obtain the information to be used in the modelling. To promote communication among participants and to encourage the active discussion, the application of the Delphi as participatory methods will be used.
Once the information is collected, the multicriteria model can be built. The MACBETH (Measuring Attractiveness by a Categorical Based Evaluation Technique) approach will be followed.

1.3. Structure of the thesis

To apply this new method, first a review of some literature is necessary. In chapter two this revision is done. Concepts such as shared decision making, models and systems that are available to enable shared decision making, participatory approaches and multi criteria decision analysis methods are further reviewed and explained.
Once the literature review is done, the case study can be designed and applied. With all this work done, an analysis and discussion of the results will be performed. Some self-criticism as well as the possible future paths of this work are also addressed.

2. Literature Review

First of all, the concept of shared decision making will be introduced as well as its main features to later move to the concept of decision aids, as a tool to help to make the decision, focusing on the patient side. With this stablished, the theoretical background in which this new method will be based can be explained. A first look at the different main participatory methods and a deeper one to the method further used, Delphi, will be made. The same thing will be done with the multi criteria decision analysis methods, focusing on the MACBETH.
The last subchapter is dedicated to the health issue under analysis: Human Papillomavirus and its vaccine.

2.1. Shared Decision Making

Shared decision making is a relative new approach in the clinical field. It has been defined as “the involvement of both patient and doctor with a sharing of information by both parties taking steps to build a consensus about preferred treatment and reaching an agreement about which treatment to implement”. [4]
It should be the norm in most medical practice for several reasons, the most important of which is an ethical imperative under the widely accepted four principles. The four principles of biomedical ethics are: [5]

- Respect for autonomy: respecting the decision-making capacities of autonomous persons; enabling individuals to make reasoned informed choices.
- Beneficence: this considers the balancing of benefits of treatment against the risks and costs; the healthcare professional should act in a way that benefits the patient.
- Non-maleficence: avoiding harm. It should not be disproportionate to the benefits of treatment.
- Justice: distributing benefits, risks and costs fairly; the notion that patients in similar positions should be treated in a similar manner.

2.1.1. Shared Decision Making history

It is possible to see the change in the medical encounter. There are several treatment decision-making models that stand out among the others; these are the paternalistic model, the informed decision-making model and the professional-as-agent model.

The paternalistic model is the usually common one used in the past. In this approach, the patient is placed in a passive role, the physician is the one that dominates the encounter and uses his skills to recommend what he thinks is the best treatment. The physician acts as guardian of the patient's best interest, without knowing the personal preferences of each patient. As this approach is not seen as a shared decision-making model because the patient involvement is, at maximum, to provide consent to

the treatment advocated by the physician, other models of shared decision-making have been formulated. [6], [7].

Nevertheless, should be noted the extent to which this approach might be, nowadays, the only feasible model: in emergency situations. [8]

As can be seen, in the paternalistic model the flow of information is unidirectional, from health professionals to patients.

The next models arose due to the recognition of the asymmetry of knowledge between the patient and the physician.

In the informed model, the patients are the ones that make the decision. The patient now has the knowledge of the clinical information, because it has been given by the healthcare professional.

Thus, once the asymmetry problem is solved, now the individual can make decisions according to their preferences and the best scientific knowledge available. [6], [7].

In this case, the information transfer is, again, just in one way but now professionals just act as a source of information, they don't have an active role in the decision-making.

The opposite case of the informed choice model is the "professional-as-agent" model; in this case the asymmetry is solved by the physician eliciting the patient's preferences. So, now is the physician the one that makes the treatment decision because he knows both information and preferences. The fact that physicians' preferences are excluded and the only ones that matter are those from the patients should be taken into account. The decision making-process is again depicted as a one-sided process. [6], [7].

In summary, in all these models of treatment decision-making that have emerged in reaction to the paternalistic model there is an exchange of information. All of them are closer to the shared-decision making model because there is a flow of information shared but the decision is always reached just by one of the parts involved. For the shared-decision making to occur there is a need for a two-way flow of information and treatment preferences. This is due to share information and share the treatment-decision are two different things in the medical encounter [6], [7]. This and the other key characteristics of the shared-decision making are presented in the section below.

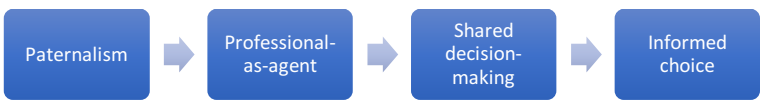

Figure 1. Continuum of decision-making.

As might be represented in Figure 1, on one side, there's the paternalistic model. It is characterized by the physician dominance in the DM process. On the other side, the informed decision-making model is placed. It limits the physicians' role to one of transferring information, patients have the ultimate control

and responsibility for the treatment decision. It has been demonstrated that many patients, for whatever reasons, prefer not to assume full decision-making control. But many may also not like the idea of not being involved at all. Shared decision-making offers an intermediate alternative for both parties. For the patient, it offers some say without total responsibility, and for the physician, an opportunity to go beyond a role of transferring information to also participate in, but not dominate, the decision-making process. [6]

2.1.2. Characteristics

Some characteristics or key criteria of this approach have been identified, which include:

- **The engagement of, at least, two participants: the physician and the patient**. This is known as a dyad relationship. It is not unusual the involvement of family member or friends and they can play a variety of different roles within (or outside) the medical encounter relating to the patient's illness, treatment selection and management. [6], [8]
- **Both parties (physicians and patients) take steps to participate in the process of treatment decision-making.** There is a need to point out that both parties need to be willing to participate and share the whole process. In the following section these steps are presented formally and explicitly. [6], [8]
- **Information sharing is a prerequisite to shared decision-making.** The specialist has to provide the patient the information that they need to know and understand to engage them in the shared decision-making process. The disease, treatments, consequences and alternatives are the components of the information given. It is important to highlight that there is also the alternative of doing nothing. Patients can also bring information obtained through other means to the encounter. In this process of sharing information, the individual learning styles of the patient knowing the patient's ideas, values, beliefs, education, culture, literacy, and age should also be exposed. [6], [8]
- **Both parties reach an agreement about the treatment decision.** For the shared decision-making to occur, there should be a mutual acceptance of the outcome. This outcome might be an agreement about the treatment decision but there is also the possibility of no agreement or disagreement. The mutual acceptance is one of the most important characteristics and a distinguishing fact of the shared decision-making. Both parties accept the responsibility for the final decision. [6], [8]

2.1.3. Steps for Shared Decision-Making.

The following steps are the suggested ones for the physician and the patient in order to share in the treatment decision-making process. [4]

First of all, physician has to invite the patient to participate in the process. An atmosphere where the patient feels comfortable and where his views and values are needed is essential in this procedure.

Patient has to know that there is no best choice about the decision and that doing nothing is also an option. Once this step is at its end, the decision to be made must be really clear, explaining and defining the problem will accomplish this as well as discussing some constrains regarding the decision such as time. [6], [7]

After that, the practitioner presents the options with the benefits, risk and side effects for each one in an unbiased simple and clear way. The options and treatments available will depend on the clinical condition of the patient, comorbidities and the services accessible in his locality. The balanced presentation of the risk and benefits of each option has to be done in a way that patient understands, it is really helpful the use of numbers when possible. It is also important to check that the patients correctly understand all the available options and the benefits and harms. [6], [7], [9], [10]

Fourthly, patient exposes preferences. Physician assists and supports patients in evaluating options based on their goals, expectations and concerns. The health professional should elicit his values, preferences, lifestyle… to allow them to understand how this may affect the decision they make.

Finally, both engage a discussion of the final decision. Professionals should support the process by explaining that it is shared and to prevent patients from feeling alone. The physician also shares his thoughts with the patient but needs to be careful to no impose his values. At the end of the process deliberation an agreement must be reached - either it is a specific treatment or doing nothing- and the following step is to assist with the implementation. [9], [10]

2.1.4. Advantages

Although SDM is a relatively new thing, there is growing evidence that it is good for patients, physicians as well as the health care system.

Firstly, SDM has been shown to improve patient decision-making outcomes. SDM helps to enlighten the modifiable factors, which often contribute to decisional conflict – the uncertainty about which procedure follow when there is no best choice. The modifiable factors are: knowledge, support, unclear values, expectations, and psychological factors such as anxiety. [9]

As lower the decisional conflict is less likely the patients are to delay the decision, be dissatisfied with it or regret it.

Knowing that, some advantages of SDM are: [9], [11]

- Improvement of patient knowledge and information recall.
- The expectations about the benefits and harms of treatment options are more realistic.
- The decisional conflict is reduced.
- Patients take a more active role in decision making without increasing their anxiety.
- The engagement and empowerment of patients are increased.

Above all these benefits, the largest and most consistent one is increased knowledge of treatment options. That is why SDM is helpful to balance the knowledge asymmetry currently existing. It helps

patients make decisions that reflect the best available scientific evidence as well as their personal preferences.

Moving to the physicians, they find SDM to be a useful strategy because it helps them in different ways: [9], [11]

- To provide pertinent clinical information about options and outcomes.
- It is a structured approach to reviewing options and outcomes.
- They stated that the involvement of patients is much higher.
- The agreement with patients is increased.
- Patient content with consultations rises up.

SDM equips patients and physicians with knowledge and skills required to make better use of time and allows the discussion to be more patient-centered (can be tailored the patient's specific needs). This benefit also increases efficiency at a health system level.

Finally, there are also some benefits related to the system. There is evidence of a reduction in the use of tests, patients tend to make more conservative judgments and choose less invasive procedures than their doctors. SDM minimize unwarranted practice variation (overuse and underuse), which leads to a reduction of the costs. With shared decision-making, patients are receiving the care that they value while still getting the care that they need.
Both parties are more comfortable with their decisions and their roles while taking part in SDM. In addition, shared decision making might lead to better health outcomes, lower litigation rates and better sustainability of health system. [9], [11]

To sum up, shared decision-making maximizes the likelihood that patient as well as physician will be respected, content and invested in the outcome. [11]

2.1.5. Barriers and facilitators

Apart from the various advantages previously seen there are some barriers that need to be addressed for a successfully implementation of the model. These barriers can be classified as well into three categories.

Try to get patients to participate in their own care is challenging. Many of them are used to the paternalistic model and still choose to be minimally involved in their care. However, with the technology and information, more and more patients prefer to be more engaged in their health care.
As before mentioned, shared decision-making provides optimal care, ethical and moral principles. When adopting it, it is needed to avoid systematic bias and inequity, which does not keep it from vulnerable patients just because it may be more difficult to deliver it to them. Rather, the process should be recommended for all patients, with adaptations to fit individuals' ability and interest. Patients can

learn communication skills and then, become increasingly confident in their ability to engage in decisions about their health.
Just to summarize, one can say that the patient barrier health care professionals face is the difficulty to carry out the model due to patients' characteristics. [11], [14]

The thoughts and perceptions of health care providers regarding SDM lead to a large numerous of barriers. Physicians perceive time as the largest barrier to adopting shared decision-making. However, there is no evidence that it requires more time. The only difference is found in how the time is spent with the physician. Actually, with the decision aids – a topic discussed in the following sections- patients are more prepared to make decisions, agree with the physician more often and increase awareness of their values, which leads to both parties being more satisfied with the patient's preparation for decision-making. Thus, SDM doesn't effect in the amount of time spent in the consultations but it does in the quality of it. [11], [13], [14]
Another barrier that physicians have to face is the shortage of SDM competences, they tend to be good at offering choices but they struggle to ask and to elicit patient's preferences. These barriers can be overcome with more education about SDM, its benefits, and how to do it properly.
Some other hurdles that physicians have to go up against might be:

- Lack of applicability based on clinical situation. For example, in an emergency situation where the patient is unable to decide and the time restriction is really big, such a thing is called selective paternalism. [12]
- Continuity of care issues, patients often see other health professionals as well.

Finally, there are also barriers in the system. By addressing and overtaking them the system-wide quality would improve. These barriers are:

- No specific funding to support SDM.
- Delivery system is intimidating to patients because of its focus on biomedical issues instead of psychosocial issues.
- Practice guidelines and policies do not reflect a SDM environment.

The current absence of financial resources does not support the specific aspects of SDM, for example the introduction of health coaches. Second, the knowledge gap between physicians and patients intimidates patients from participating in their care because the encounter might be more focus on its biomedical issues instead of psychosocial ones. Lastly, there are no practice guidelines and policies available for those who want to improve quality of care through SDM. [11]

Despite the current lack of systemic support for and knowledge about SDM, there have been some advances in the past couple of years toward adoption of this new approach. [13]
Moving now on to the facilitators for shared decision-making, there are three most common ones cited by physicians are: [11], [14]

1. Provider motivation.
2. Positive impact on clinical processes.

3. Positive impact on patient outcomes.

Therefore, the facilitators mentioned above are what would help SDM implementation. Decision makers should take advantage of them and combine these facilitators with other strategies to increase stakeholder participation for adopting SDM. [15]

2.1.6. Possible improvements and future

1. If patients understand the reason for the treatment they are offered, and are fully conversant with the possible side-effects before they begin treatment, they are more likely to adhere to the treatment regimen than if they had no active part in the decision-making process. [7]
2. The goal for the future is to embed SDM in current system and, as an ultimate goal, try to make it not seen as a tedious added extra but as the core of good clinical practice, with patients placed fully at the center of the decision. [9]
3. Decision-making is a complex intervention, and its implementation in healthcare will need multifaceted strategies together with culture change among professionals, organizations, and patients. This change starts with increased awareness at all levels of society. [9]
4. It is ethically preferable and it is also beneficial for patients, physicians as well as the health system.

- Change the physician behavior, would help to implement this system: [9]
    - The distribution of printed educational material
    - Educational meetings
    - Audit and return
    - Reminders
    - Interventions (any intervention designed to change the professional's behavior through interactions with the patients) such as coaching.

2.2. Decision aids.

As has been said so far, the vast majority of decisions in medicine are not evident. Patients and clinicians need to discuss the options by using the best clinical evidence and make mutual decisions taking into account the patients' context, values and preferences. Hence, implementing shared decision-making is not an easy task. Doctors need the aptitudes and tools to do it in a trustable environment and patients need information and support. Besides, patients need to have a bigger role in developing strategies to enhance the process.

Another important ingredient is the access to best evidence. Hitherto, the generation and dissemination of clinical practice guidelines have been focused on meeting the clinicians' educational needs.

Patients have had difficulties to find reliable and accessible information that supports shared decision-making. Recently, some summaries and practice guidelines understandable by patients are being developed. [16]

Each medical encounter is influenced by a wide variety of factors. Some of them are related with patients' circumstances and their medical requirements as well as their beliefs. Those arise from what they have read, personal experience, family and friends' recommendations and the media. That is why is important to provide patients with precise, objective, up to date evidence on the benefits and risk of the alternatives and their effect on outcomes that matter to them. [17]

Treatment decision aids are a form of educational mediation. But they are also aids to decision-making because they provide a way of structuring the decision-making and structuring the process into specific and sequential steps. [1] Communication techniques that allow the patient to adequately weight the risks and benefits associated with their choices are essential skills for shared decision making.
On the clinicians' side, they have to communicate effectively to build a trustable and solid relationship. Improving communication skills of professionals may impact people's experience. The topic about professional educational programs to provide training in communication is increasingly seen as an essential part for a good SDM practice. Implement this training is a challenge due to the large community it affects, plus these skills need to be reinforced over time, the frequency with it has to be made is still a topic under discussion. [18]
Combining the education of professionals, such as sessions integrated into a degree program or workshops, plus a patient decision aid improve highly the use and satisfaction of shared decision-making. [19]

Patient decision aids are tools designed to help people join in decision making about health care options. They provide detailed evidence-based information about patient's treatment choices, outcomes, the probability of them and quality of life associated with each outcome. They have been developed as adjuncts to consultation to prepare patients to participate in the decision-making process. PDA help patients clarify and communicate the personal value they associate with different features of the options. Patients are, thereupon, prepared to make informed, values-based decisions with their physician.

Consequently, PDA are used for complex decisions that need more detailed information and more careful consideration. Sometimes the scientific evidence about options is limited. Hence, the best choice depends on the personal importance the patient places on the benefits, harms, and scientific uncertainties. The main difference of PDA is that here the information about the options is presented in a balanced, personalized way and in sufficient detail that patients are able to judge their value.

On account of these, one can figure out the aim of decision aids. It is to improve the quality of decisions. By quality is understood that the interventions chose by patients are in accordance with their informed

and considered values. The features of options that patient value may include the health states that might be affected by the option selected, their attitudes towards the possibilities related with each option, their willingness to make trade-offs over time and other issues relevant to the decision, such as beliefs about the acceptability of particular procedures. [20]
The reduction of unwarranted practice is another aim of the decision aids. The way that they accomplish these two aims is by proving facts about the condition, options, outcomes and probabilities; as well as clarifying patients' values –what matter most to them- and guiding patients in the deliberation and communication so that the choice reached is made according to their informed values.

With everything seen above, it is easy to figure out some of the main advantages of PDA; the decisional conflict is lower, they feel more comfortable with their choices, the decision-making process is quicker. Patients exposed to decision aids participate more actively in decision-making and are less likely to remain undecided. The quality of the decision is improved because patient decision aids increase knowledge and understanding of options and outcomes, enhance realistic and more accurate expectations of outcomes of options, and improve agreement between patients' values and the subsequent chosen option. [1]
People who use decision aids generally feel more informed about options and clearer regarding their personal values, which leads to a higher patient satisfaction, PDA improve individuals' perception of involvement in decision.
On the side of the physician there are also some benefits while using patient decision aids; informed patients require less time to clarify confusion and to educate them because they do not misunderstand the information available on the Internet. Similarly, there is a higher quality consultation, which leads to a higher provider's satisfaction. As patients are actively involved in their care, they are less likely to seek an alternative provider. [21], [22]

If one looks for patient decision aids in the net a huge amount of them would appear. There are more than 500 PDA for a lot of medical conditions available and others being developed by many different groups around the world. So, how can we know if they are a reliable source of health information that can help us? It is important to mention that if the decision made is based on mistaken information or this information is influenced by poor presentation, low-quality communication formats or by com kind of interest would be a threat to patient's health condition.
This same question was a topic for a group of researchers, practitioners and stakeholders from around the world that in 2003 decided to join and establish the International Patient Decision Aid Standards (IPDAS). Thus, it was created with the purpose of improving the quality and effectiveness of PDA. In order to accomplish it, an internationally validated set of criteria for improving PDA's content, development, implementation and evaluation was built. These criteria are helpful, for evaluating PDA quality, to a wide variety of individuals and institutions that use or develop them. They can determine whether a PDA included the suggested components and meet agreed upon quality criteria across various dimensions. [23], [24]

The checklist proposed for IPDAS can be divided into three sections:

- Content
    - Provide information about options in sufficient detail for decision-making.
    - Present probabilities of outcomes in an unbiased and understandable way.
    - Include methods for clarifying and expressing patients' values.
    - Include structured guidance in deliberation and communication.

- Criteria related with the development process.
    - Present information in a balanced manner.
    - Have a systematic development process.
    - Use up to date scientific evidence that is cited in a reference section/technical document.
    - Disclose conflict of interest.
    - Use plain language.
- Criteria related with effectiveness
    - Ensure decision-making is informed and values based.

2.2.1. Types of patient decision aids.

There are a lot of different types of patient decision aids with different formats and to be used at different time or in different situations.

Let us focus first on when are they delivered. The ones introduced before the meeting, which are the vast majority of PDA, are called pre-encounter decision aids and their main purpose is to provide extensive information. When the decision aids have been designed for use in clinical encounters- encounter decision aids- their role is to facilitate conversations about available options between patients and providers while it occurs. They are meant to support preference elicitation and to enable clinicians to tailor information to patients' needs and characteristics. The information comprehended in these ones is basically pictures, short sentences, icons designed for assimilation in a short period of time, frequently used to help structure the conversation between both parties. These types of DA, however, have not been the matter of as much study as pre-encounter decision aids. [24]

Ergo, patients may use them to prepare for talking with a clinician, or a clinician may provide them at the time of the encounter to facilitate decision-making. There may be other people involved with whom decision aids can be used, such as family members or health educators.

As has been said, these tools help patients to personalize the information, to understand that they can choose among various options, to appreciate the scientific uncertainties inherent in that choice, to clarify the personal value or desirability of potential benefits relative to potential harms, to communicate their values to their practitioners, and to gain skills in the steps of collaborative decision making. [25]

There are different ways or formats of delivery, the most common ones are booklets, audio-guided booklets, video/DVD, decision boards, computer interactive programs and many developers are moving toward web-based platforms. [1]

Some of them are used for treatment situations while others for prevention actions. In any case, these tools allow for interaction between participants. As maximum, there are some of them that include some patient's opinion or review favorable and against each option.

The personal stories vary in their content, delivery and length. But all of them provide information about the patient's perception and experience of making the decision and the health context that can be taken into consideration when a person makes his or her own decision. They can be narrated in first person, as a third-person person scripted narrative describing other patients' experiences or can illustrate conversations between patients and others. [26] Patients consider important the opinion of other patients that went through the same health problem while making their own decisions. Personal stories have the potential either hinder or facilitate an informed decision making by the patient. The way of implementing them to improve the efficacy of PDA and if is really effective to include them is being under evaluation and needs to be explored deeply. [27]

2.2.2. Decision Aids Tools. Some Examples and main providers.

Bearing in mind the huge and different amount of available patient decision aids, a few different ones among them, and where can be found, are going to be mentioned, for a better comprehension of what and how they are.

- The Mayo Clinic started to develop its own decision aids in 2005 and since then distributes them for free to other health care providers, they are designed to be used during the medical encounter, with clinicians working alongside patients. [28] They are easy to use tools that provide graphic displays of the benefits and harms of different options organized around concerns that are important to patients.
- Option Grids is an initiative of The Dartmouth Institute. It is one-page summaries that provide answers to patients' frequently asked questions, covering clinical outcomes and practical concerns faced in daily life. They are designed to be used face-to-face in the clinical encounters or to be given to patients, before the conversation with a provider. [29]
- The Patient Decision Aids Research Group is a non-profit academic health research group, which belongs to OHRI (Ottawa Hospital Research Institute), established in order to help patients facing tough decisions. They created the Ottawa Personal/Family Decision Guides, which can be used for any health decision. It also has an inventory that allows searching for a decision aid on particular health topic. [30]

- HEALTHWISE is a nonprofit group, which provides a huge amount of decision aids for different topics. They are videos, educational literature, and/or interactive tools that patients typically use on their own time to learn about their treatment options, know which decision would they take by evaluating their personal feelings and they also hear from patients who have decided to undergone or have chosen to not. [28]

After these research, along different providers and their decision aids, can be concluded that their main purpose is to better inform patients about their condition and options. Although some do ask for patients' preferences too, there is a lack of decision aids focused on helping the physicians to better understand their patients' values and preferences

2.3. Participatory Methods

A participatory approach has the main objective of involving all participants in the process of gathering information and decision making in order to reach a compromise when there are a wide variety of opinions. These methods are important in dealing with uncertainty and equity in decisions. With a group decision, it is possible to bring together as much experience and knowledge as possible on the theme and to create a solution where all participants contribute their opinions. There are three different levels of participation: [31]

- Information's transmission (unidirectional).
- Consultation (bi-directional, but the consulted party states the decision)
- Active participation (all the participants are engaged in the discussion and decision).

Henceforth, there is only going to be reference for the active participation. It is possible to use different methods; its application depends on the problem. In deciding which method employ, it is needed to pay attention to different elements such as the objectives, topic, participants, the amount of time available and the budget.

Some of the main methods are presented below.

2.3.1. Charrette.

Charrette is an intensive face-to-face process designed to bring people from various groups of society into consensus within a short period of time. The main group is divided into sub-groups, who report back to the whole group and feedback from the whole is then addressed to them. This process is repeated until consensus is reached at the final deadline for a report. The size can vary from 50 to over 1,000 people, and in time, from four days to two weeks. This model has often been applied to development, design and planning projects at the local community level. [31], [32]

2.3.2. Citizens Jury.

The Citizens Jury method is a mean for obtaining all the possible views of informed citizens as an input into policy decisions. The jury is composed of 12-24 randomly selected citizens, who are informed by several perspectives. The sponsoring body – any level of authority- is required to respond to the report either by acting on it or by explaining why it disagrees with.
Citizens Jury method has been applied to a wide range of topics, including economic, environmental, social and political issues. It is most applicable when one or more alternatives to a problem need to be selected and the various competing interests arbitrated. [31], [32]

2.3.3. Expert panel.

The expert panel method congregates a group of experts. They share their expertise and produce a report that provides a vision and/or advices for future possibilities and needs for the topics being analyzed. This method is particularly appropriate for issues that require highly technical knowledge and/or are highly complex and require the synthesis of experts from many different disciplines. [31], [32]

2.3.4. Focus Group.

A Focus Group is a planned discussion among a small group (4-12 persons) of stakeholders. It is conceived for gathering information about the preferences and values, pertaining to a certain topic, of each member. Focus groups are good for initial concept exploration, generating creative ideas. They are most appropriate to get a sense of regional, gender, age and ethnic differences in opinion. [31], [32]

2.3.5. Participatory Assessment Monitoring and Evaluation.

PAME (Participatory Assessment Monitoring and Evaluation) is a deliberation between the stakeholders of a project to analyze the difficulties already overcome and to make decisions about the future. This method can be conducted as part of a broader participatory process or as a separate exercise. [31], [32]

2.3.6. Planning Cell.

The Planning Cell method consists in a small group (approximately 25 individuals) selected in a random way, who will be in charge of present solutions for a given planning or policy problem. Participants acquire and exchange information about the problem, explore and discuss possible solutions and evaluate these in terms of desirable and undesirable consequences. The final results are summarized as a ‘citizen report’, which is delivered to the authorities as well as to the participants themselves. [31], [32]

2.3.7. Scenarios Workshops.

Scenarios Workshops are a technique to describe potential futures that focus attention on relationships between events and decision points, evaluating the decisions' impacts and the uncertainty of each event. Scenario construction is useful in situations where the past or present is unlikely to be a guide for the future. [31], [32]

2.3.8. World Café.

The World Café is a creative process for promoting dialogue and the sharing of information and opinions to create a living network of conversation. In order to share this information, a café atmosphere is created. Smalls groups of participants the tables. At regular intervals, the participants move to a new table, in each table there is always someone who remains to summarize to the new group the previous conversation. It is an informal way of sharing information. [31], [32]

2.3.9. Delphi.

Delphi focuses "on a systematic collection and aggregation of informed judgement from a group of experts on specific questions and issues" [33] with the aim of "to obtain the most reliable consensus of opinion of a group of experts." [34]

To this end, Delphi has four necessary characteristics to work, its main key features: [35]

- **Anonymity**. Anonymity is assured by using questionnaires.
- **Iteration.** The questionnaire is presented more than one time.
- **Controlled feedback.** It is given between rounds with the information of the previous round.
- **Statistical aggregation of group response.** At the end of the process, the group's judgment is taken as a statistical average (mean or median) on the panelist's answers of the final round.

The Delphi method is an iterative survey of experts. Each participant must complete a questionnaire. The method consists of different rounds, at least two, of a questionnaire and, at the beginning of the following round it gives the feedback of the previous round's results. With this information, the questionnaire must be filled again and the participants can alter their original assessment or stick to it after knowing and evaluating the viewpoints of the other participants. This process is repeated as many times as is useful. In most Delphi processes the level of agreement increases from round to round. [31], [32], [36]

This method can be applied in a variety of areas such as government studies, environment studies, medical studies, social studies or business and industrial research. Due to this wide range of areas, ten different types of Delphi designs had been identified: classical, modified, decision, policy, real time/consensus conference, Web-Delphi, technological, online, argument and disaggregative policy. These designs have different purposes, administration methods and have different number of rounds. [37]

Exist some main key aspects to consider while applying the method. These can be first structured in four phases: Delphi preparation, Delphi design, Delphi implementation and Delphi evaluation.

In the Delphi preparation is where the panel will be composed by identifying and selecting the experts, they need to be carefully selected. Some criteria to include them or not can be the experience and knowledge of the issue being investigated or the willingness and capacity to participate. [38] The size of the panel is another decision that must be taken at this step. [39] The preparation of evidence and data as well as the development of accompanying text are also carried at this stage. The preparation step is really important. If it is not carried out appropriately, it could affect negatively in the response rates. respondents have to be informed of what they will be asked to do, how much time they will be expected to take and what use will be made of the information. [40]

For the Delphi design, aspects such as the first round (open ended question or a closed round) and the total number of rounds, the number of questions and response categories, the feedback and the stopping criteria are included. The total number of rounds depends either on the level of agreement stablished as "stopping criteria" or it is stablished before the process begins. Control feedback is one of the key features of the Delphi, it is the trigger for success of the process. It can be presented as summary statistics, rationales or both. [37], [40]

In the implementation phase the timing, management and documentation of results should be taken into account. The communication during the rounds must be high. Documentation of results includes consistently recording divergent views at a similar level of detail. [41]

Finally, for evaluation aspects as reliability and validity, trustworthiness and post-group consensus (the degree of participants individually agree with the final group aggregate) must be taken into consideration. [40], [42] To ensure trustworthiness four criteria should be satisfied: credibility of the data, stability of data (dependability), objectivity (confirmability) and transferability meaning the application of the findings to other settings. [41], [43]

Finally, the main strengths and weaknesses of using this method are summarized in Table 1:

Strengths	Weaknesses
A rapid level of agreement can be achieved	Does not cope well with widely differing opinions or large changes in opinions (paradigm shifts)
Participants do not have to be in the same room together to reach agreement	The facilitator's view may dominate in the analysis
Individuals are able to express their own opinions as opposed to "Group think"	Differing opinions may not be sufficiently investigated
Can include a wide range of expertise	Can be time-consuming
Relatively low cost to administer and analyze	Needs high participant motivation
There is the potential to gain large quantities of data	Success of the method depends on the quality of the participants
Offers a method which can be used where data are lacking	The written response format may be less suitable for some potential respondents

Table 1. Strengths and weaknesses of the Delphi method. [44]

2.4. Multi Criteria Decision Analysis Methods

2.4.1. Introduction

The proven fact of having difficulties making a decision when facing an unfamiliar problem and involving value based trade-offs between the options has entailed the development of a number of multi-criteria decision-making methods. Multiple criteria decision analysis (MCDA) is a structured approach that can be defined as: "an umbrella term to describe a collection of formal approaches, which seek to take explicit account of multiple criteria in helping individuals or groups explore decisions that matter". [94] Hence, these techniques are designed to help people make better choices (that are consonant with their preferences and values) and they are especially useful in situations that involve tangible and intangible considerations. The steps involved in using a multi-criteria method are comparable to the essential elements of a SDM process. This parallelism, depicted in the Table 2 below, suggests that they can be used as clinical decision support systems that will facilitate implementation of high quality shared decision-making. [45]

SDM	MCDA
Definition of the problem and options available	Create a decision model that contains the goal and options and criteria involved.
Review of options' pros and cos	Pairwise comparison regarding how well options satisfy criteria
Elicitation of patient values and preferences	Pairwise comparison to prioritize factors affecting the decision (the criteria)
Clinician recommendations	Review results using clinician's perspective
Check for clarity and understanding	Detailed review of model results, sensitivity analysis.
Make a decision	Use the results

Table 2. Steps in SDM and MCDA. Parallelism. [45]

In this type of approach the figure of a facilitator, an external actor- specialist in decision analysis- who assists the decision-maker along the process, is usually involved. Depending on the MCDA method adopted the role facilitator/specialist change:

Model of consultation	Approach	Goal	Learning provided
EXPERT model	Normative	Fix client's problem	Adaptive or single loop. Client. Consultant. 
DOCTOR model	Prescriptive	Fix client's problem together with the client	More adaptive than generative.
HELPER model	Constructive	Increase client's *capacity of learning*	Generative, double loop. 

Table 3. Types of consultation. [46]

The previous table shows that for a SDM context, the approach to be adopted is the constructive one.

The constructive approach is a socio-technical approach. The social component aims to capture the points of views of participants, creating a "shared understanding of the issue". [46] The way to obtain the social aspects is the participatory methods, presented in the previous chapter. Technical elements allude to the techniques to support the different steps of the development of an evaluation model, the MCDA methods. [47]

There are a lot of different MCDA techniques. All of them have in common an attempt to be clear about the criteria and how they influence the decision. Which one to use will depend on the nature of the decision-making process. For example, in the case of the value measurement task, the way decision maker judges the options and criteria may affect the approach selected: [48]

- Measuring the relative value of the options in each criterion:
  - Numerical (e.g. direct rating)
  - Non-numerical approaches (e.g. MACBETH)
- Criteria weighting procedures:
  - Numerical techniques (e.g. swing weighting)
  - Non-numerical techniques (e.g. MACBETH)

Testing the impact on the decision to be made of a variety of weightings across criteria is essential to using MCDA well. It is also something that MCDA tools make easy.

The range of possible MCDA approaches is extensive but all of them have important features in common, which are summarized in the box below. It helps to be realistic about what MCDA does and does not do. It is important to bring to mind that no form of MCDA can avoid the need for value judgements. [48]

What does MCDA do?

1. Given a set of criteria, and weights for them, MCDA structures and combines that evidence to suggest a best choice, or a ranked list of options from best to worst, and can test the sensitivity of the choice or ranking to varying the weights for the criteria.
2. The preferred options identified by MCDA are likely to out-perform the use of intuitive judgement alone.

The decision theory and psychology literature abounds with examples of the various biases and heuristics that are evident when individuals are confronted with complex decisions (Kahneman 2003; Gilovich et al 2002). This is because the consideration of multiple criteria is cognitively demanding – arguably especially so when decisions are made in a committee context.

What doesn't MCDA do?

1. MCDA does not decide which criteria to include. That remains a matter for judgement.

There are various means by which that judgement might be reached. The list of 'other considerations' currently used by NICE provides a starting point. Another approach might be to engage in a consultative process with the general public, to obtain wider views on what other factors should be taken into account.

2. MCDA does not decide what weight to place on each criterion. That remains a matter for judgement.

Some MCDA tools (e.g. 1000Minds) incorporate into their approach a means by which the weights might be determined by asking samples of participants (who could be the decision makers themselves or the general public) to make a series of pairwise choices, through which their preferences (i.e. the weight they attach to each criterion) can be discerned. Even that approach relies on a prior judgment about whose preferences and priorities should count – a non-trivial judgement in itself. Many MCDA tools do not incorporate that sort of preference based approach, and rely instead on some other means of assigning weights to each factor. MCDA approaches that rely on arbitrary scoring and weighting (i.e. decided by the researchers rather than by others whose views are relevant) must be treated with extreme caution, as the weights may have little relationship with the relative importance society places on those factors.

3. MCDA does not replace decision-making – it facilitates it.

The purpose of MCDA is to clarify what choice would be made, if the criteria included are the only ones that matter, and if the weights applied to those capture consistent social preferences. But there may well be other, one-off considerations which are relevant to particular decisions. In these cases, decision-makers can judge such considerations to outweigh usual considerations. The use of MCDA will, however, require such departures to be carefully – and explicitly – justified.

Figure 2. What does MCDA do? What does MCDA not do? [48]

2.4.2. MACBETH

MACBETH (Measuring Attractiveness by a Categorical Based Evaluation Technique) approach allows to judge the attractiveness between options by comparing them in a non-numerical way, using seven possible different semantic categories: *no, very weak, weak, moderate, strong, very strong* and *extreme*. This is the main difference from other MCDA approaches: it only requires qualitative judgements about differences of attractiveness between two options at a time, in order to generate numerical scores for the options in each criterion and to weight the criteria. [49]

The ideas upon it was created are still being its essential characteristics: It is a humanistic, interactive and constructive approach to the problem of how to transfer the verbal qualitative judgements to a quantitative model of values, which allow the path from ordinal to cardinal preference modelling, particularly analyzing judgmental inconsistence and offering suggestions to progress with the method. [53]

As any other MCDA method, it can be firstly seen as 3-main processes: Structuring, Evaluation and Interpretation and Final decision: [47], [50], [51], [52]

- Structuring: the problem to be solved should be clear as well as the options, the decision-maker and all the possible stakeholder identified, the criteria stablished together with its descriptor of performance.
- Evaluating: The performance of the different alternatives for each criterion is transformed into value and the weights of the criteria are defined by the decision maker. The value of each alternative in each of the criteria is aggregated in order to obtain its overall value (additive value).
- Interpretation and final decision: A sensitivity and robustness analyzes are performed on the results and will lead to the more attractive decision.

MACBETH user guide provides a step by step account of the use of the technique. They are detailed in Figure 3.

An emphasis on the role of sensitivity analysis should be done. Given that uncertainty may be a factor both in the evidence being considered, and in the MCDA process, then exploring the sensitivity of suggested decision outcomes is a key part of the decision process. [48]

STRUCTURING

1. Define the options to be appraised.
2. Build the value true and define criteria. The criteria for assessing the consequences of each option had been together with their descriptors of performance are introduced in the program.

EVALUATING

3. ‘Scoring’. To assess the value associated with the consequences of each option for each criterion.

3.1. Rank within a criterion. This is not compulsory, but recommended.

3.2. Qualitatively judge difference of attractiveness within a criterion.

3.3. Check the consistency of the scores on each criterion.

3.4. Quantify attractiveness within a criterion.

4. 'Weighting'. Assign weights for each of the criteria to reflect their relative importance to the decision.

4.1. Weight references. To weight the model's criteria two references (one "upper" and one "lower") of intrinsic value in each one of the criteria need to be defined.

4.2. Rank the weights. The ranking of criteria weights is determined by ranking the "overall references" in terms of their overall attractiveness. Although recommended, this is not compulsory.

4.3. Qualitatively judge differences of overall attractiveness.

4.4. Quantify the weights.

INTERPRETATION AND FINAL DECISION

5. Analyze the model's results

5.1. Overall scores. The results are presented in a concise table.

5.2. Overall thermometer. Option's overall scores can also be displayed graphically.

5.3. Option's profile. In order to gain a more comprehensive understanding of the model's results, M- MACBETH allows to learn the extent to which an option's scores contribute to its overall score.

5.4. Differences profiles. Allows to explore the differences between the scores of any two options.

5.5. XY mapping.

5.5.1. Comparing scores in two criteria or groups of criteria. Allows to display the model's results in a two-dimensional graph ("XY Map"), enabling to compare the options' scores in two criteria or groups of criteria.

5.5.2. "Cost-Benefit" analysis. If want to create a two-dimensional cost-benefit graph that contrasts each option's overall score (benefit) with its respective cost. For this purpose, M-MACBETH allows to associate a cost to each option, without entering a cost node into the value tree.

6. Sensitivity and Robustness Analyses.

6.1. Sensitivity analyses. Sensitivity analysis on a criterion weight allows to visualize the extent of which the model's recommendation would change as a result of changes made to the weight of the criterion.

6.2. Robustness Analysis. Making decision often involves incomplete, imprecise or uncertain information. It can, therefore, be useful to explore the extent to which conclusions can be drawn given varying amounts of information, of differing degrees of imprecision or uncertainty.

Figure 3. Applying MACBETH – detailed steps [48], [49]

In the multi criteria value measurement framework (evaluating stage), MACBETH is used to build value functions and weight criteria in additive models. For building value functions, it is used the questioning protocol. During this questioning protocol, a matrix with the categorical judgments of the DM is filled. For each qualitative judgment introduced, the consistency is verified, if needed, offers suggestions to solve eventual inconsistencies. Once the consistency is assured the software, by mathematical programming, determines an interval numerical scale which has to be analyzed and validated by the DM. [51]

1.1.1.1. Structuring

Typically, this approach starts by a structuring phase. Once the problem has been defined and the alternatives defined, it is time to identify and agree on the relevant criteria by which the options will be evaluated.

The criteria might already exist and be part of a well-established decision-making process or it could be established as a first step. There are a lot of means by which appropriate criteria might be suggested, such as using a participatory approach aforementioned. The criteria to be included in will need to have some characteristics: The criteria should be clearly defined. The criteria should be mutually exclusive and non-redundant; criteria must not describe overlapping consequences of the options. Criteria should adequately describe only all the important consequences (be complete and concise) as well as help any interested individual to conceive them (be intelligible). They must be operational, meaning that each option can be judged/described in each criterion. [48], [54], [55]

When the criteria are validated, it should be made operational for evaluating alternatives. This means need to be accompanied by a way of describing the options in terms of those criteria. This is done by associating a descriptor of performance for each criterion. A descriptor of performance *is "an ordered set of plausible impact levels in terms of a particular criterion, intended to serve as a basis to describe, as much as possible objectively, the impacts of actions with respect to that criterion".* [53] They allow to turn the criteria comprehensible, providing a performance scale that allows characterizing an option's performance on each criterion. [55]

There are different types of descriptors, as seen Figure 4: [55]

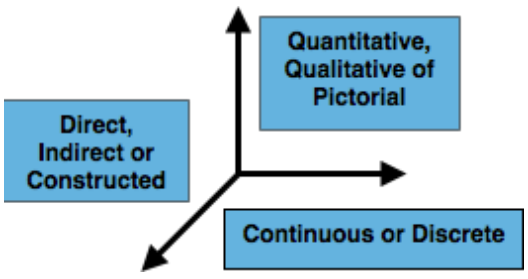

Figure 4. Typology of descriptors. [55]

- Its scale can be: direct (related to the criterion in a natural way. Directly reflect effects), indirect (indicates causes more than effects) or constructed (describe characteristics underlying the criterion).
- If the descriptor uses numbers, it is a quantitative descriptor whether if it uses semantic expressions and numbers it is a qualitative descriptor. When it is a visual representation it is called "pictorial descriptor".

- A discrete descriptor would be represented by a finite set of impact levels while a continuous descriptor would be represented by a continuous function.

Once the criteria have been identified, they can be structured using “value trees”, which decompose the overall value into criteria and sub criteria in a visual manner. [56]
When describing the performance of the options in each of the criteria. Two reference levels should be identified, assigning the scores 0 and 100 to the lower and upper references, respectively. [49]

1.1.1.2. Evaluating

The following step is qualitatively judging the difference of attractiveness of the options within a criterion. The performance scale is converted to a value scale by these judgements. Judgmental disagreement or hesitation between two or more consecutive categories is allowed. Each time a qualitative judgment is elicited, the consistency of all the judgments previously inserted is verified and suggestions are offered to resolve inconsistencies if they arise.
The M-MACBETH software determines an interval within which each score of each option can vary when the other scores are fixed and still remain compatible with the matrix of judgements. This allows the adjustment of the scale by comparing differences of scores and quantifying attractiveness within a criterion. [49], [57]
Usually, in the MACBETH approach, two distinct levels of reference performance are defined: a level called "Neutral" and a "Good" level. From the definition of these two levels, the decision-maker's judgment process is made easier due to the two established references. [49]

In order to evaluate the option -and in this way to know the overall value- the value scores on the criteria for each option requires its conversion to a common value measurement scale. This is the scaling role of the weights that were assigned.

After evaluating the attractiveness of the actions in each concern and knowing the value scores, the final step is to acquire the overall attractiveness of the options. In order to evaluate an option, the value scores on the criteria of the option should be aggregated, which requires a “harmonization” of the value scales, meaning its conversion to a common value measurement scale. Hence, the first step to follow is assign weights for each of the criteria to reflect their relative importance to the decision. When the weights and scores for each option are combined it leads to the overall value of the options. The overall attractiveness of an alternative is computed for MACBETH following the mathematical elements of the additive value model (equation 1): [47], [57]

$$V(a) = \sum_{j=1}^{n} k_j v_j(g_j(a)) \qquad \sum_{j=1}^{n} k_j = 1 \qquad \begin{cases} v_j(best_j) = 1 \\ v_j(worst_j) = 0 \end{cases} \qquad (1)$$

Being:

- V(a) the overall value of option a.
- $g_j(a)$ the performance on criterion j of option a.
- $v_j(g_j(a))$ the respective value scores.
- k_j the weight assigned to the criterion j.

1.1.1.3. Recommendations.

Once the model has been built, a table of options' scores is presented. In order to gain a more comprehensive understanding of the results, the program allows several graphical representations. It permits to see the extent to which an option's scores contribute to the overall score, to view the differences between the scores of any two options or compare options' scores in two criteria, among others. [49]

The software also allows to carry out a sensitivity and robustness analysis of the results. This would help to understand the problem in a deeper way, to adjust the model as well as to create convictions about the priorities to be established or options to be selected. [49]

2.5. Human papillomavirus

Human papillomavirus (HPV) is the most common sexually transmitted infection (STI) worldwide. It is really common, nearly all sexual active people are infected at some point of their lives. In the United States, for example, about 14 million people become infected each year. [58] It can be spread through many types of genital contact, it is transmitted by skin-to-skin contact, which means intercourse is not necessary. Most infections clear on its own and people never develop symptoms or health problems, they may spread it to others without knowing it. There are currently no available medicines to treat HPV infection.

2.5.1. Health problems

Exist more than 150 types of HPV. Some persistent types can cause health problems including genital warts and cancers. [59] More than 40 types of HPV that can affect the genital area as well as the mouth and throat, but 9 of them are known to cause the majority of HPV-related cancer and diseases. These are types 6, 11, 16, 18, 31, 33, 45, 52, and 58. The problems these 9 types caused can be divided into two types: low risk types, the ones causing genital warts, and high-risk types, which may lead to different types of cancer.

2.5.1.1. *Low risk types*

Low risk types may also be called nononcogenic HPV types, because they do not cause cancer. In this group, there are HPV types 6 and 11, they cause approximately 90% of all genital warts. [59]

Figure 5. Anal warts. [60]

2.5.1.2. *High risk types*

High risk HPV types or oncogenic types can cause different kinds of cancer. HPV types 16, 18, 31, 33, 45, 52, and 58 are included in this group. Infections with these types can cause:

- cancers of the cervix, vagina, and vulva in women;
- cancers of the penis in men;
- cancers of the anus and back of the throat, including the base of the tongue and tonsils (oropharynx), in both women and men.

It is important to mention not all cases of these cancers are caused by HPV. Although these 7 types of HPV are responsible for about 90% of cervical cancer cases and approximately 70% to 75% of vaginal cancer cases, 30% of vulvar cancer cases, and 85% to 90% of anal cancer cases are HPV related. [59]

2.5.1.3. *Burden of HPV related cancers.*

According to available data about the burden of HPV-related cancers will be presented.

Cervical cancer is the fourth most common cancer among women worldwide, and the seventh overall, with 527,624 new cases and 265,672 deaths in 2012, being the 7.5% of all female cancer deaths. In Portugal, 720 new cervical cancer cases are diagnosed each year and about 390 deaths occur. [61], [62]

Anal cancer is a rare type of cancer in the general population, its number of incident cases is 40,000., There are an estimated 35,000 new cases every year HPV related, 17,000 of them corresponding to males and the other 18.000 to females. [61], [62]

Cancer of the vulva is unusual among women worldwide, approximately 34,000 cases per year yet only 8,500 of them is attributable to HPV. [62]

Vaginal cancer is less common than vulvar carcinoma, with 15,000 estimated new cases in 2012 but 12,000 ascribed to HPV. [62]

The annual burden of penile cancer has been estimated to be 26,000 cases, 13,000 of them attributable to HPV. [62]

When referring to head and neck cancers, approximately 38,000 cases per year are attributable to HPV. Around 30% of oropharyngeal cancers are caused by HPV infection (29,000 cases per year). The incidence in men is much greater than in women: 24,000 cases for men and 5,500 for women. For cancers of the oral cavity only the 2% might be linked with the virus (4,400 cases per year, representing 2,900 male cases and 1,500 women cases) and for larynx cancer, the percentage is approximately the same (3,800 cases per year, resulting of 3,300 male cases and 460 female cases. [61], [62]

To sum up, an estimated 635,700 new cancer cases worldwide were attributable to HPV in 2012, which lead HPV to being as one of the most important infectious causes of cancer. Cervical cancer represents the 83% of the total burden of cancer attributable to HPV, which generated a greater awareness of the virus among the female population. [62] The most common cancer among male population is oropharyngeal cancer. All this information is summarized in Table 4.

HPV-related cancer site (ICD-10 code)	Number of incident cases	Number attributable to HPV	AF (%)	Number attributable to HPV by gender	
				Males	Females
Cervix uteri (C53)	530,000	530,000	100.0	0	530,000
Anus (C21)	40,000	35,000	88.0	17,000	18,000
Vulva (C51)	34,000	8,500	24.9	0	8,500
Vagina (C52)	15,000	12,000	78.0	0	12,000
Penis (C60)	26,000	13,000	50.0	13,000	0
Oropharynx (C01, C09–10)	96,000	29,000	30.8	24,000	5,500
Oral cavity (C02–06)	200,000	4,400	2.2	2,900	1,500
Larynx (C32)	160,000	3,800	2.4	3,300	460
Total HPV-related sites	1,200,000	630,000	54.0	60,000	570,000

Table 4. Number of cancer cases attributable to HPV and corresponding attributable fraction (AF) by cancer site and sex. [62]

2.5.2. Symptoms of HPV infection.

As said, often there are no symptoms of an HPV infection, and the body's immune system clears the infection on its own in a few years. Many people never know they were infected. But sometimes an infection will last longer.

A sign of genital HPV infection are genital warts. These can be raised flat, pink or flesh-colored. Their shape can be like small cauliflower bumps or like tiny stem protrusions. Their number and size can vary. In women, genital warts appear on the vulva but can also occur near the anus, on the cervix or in the vagina. In men, they grow on the penis and scrotum or around the anus. Genital warts rarely cause discomfort or pain, although they may itch. [64], [65]

When talking about high-risk HPV types, often symptoms do not appear until the cancer is in later stages of growth. It is possible to have precancerous changes in cells in the tissue without any symptoms. That is why regular checkups are so important. In many cases, cancer can be prevented by finding abnormal cell changes that, if left untreated, could develop into cancer. [64]

2.5.3. Risk factors

Although get infected by HPV is common, some factors may lead to an increased risk for developing HPV- related health problems. This includes:

- **Multiple sexual partners.** People are more likely to contract HPV infection if they have more than one sexual partner. This includes having sex with a partner who has had multiple sex partners.
- **Weakened immune systems.** People with a weakened Immune system due to HIV/AIDS or by immune system-suppressing after organ transplants are at increased risk for HPV infection. [64],[66]
- **Smoke**. Smoking increases HPV infection prevalence**.** [67]
- **Be a non-circumcised man or being with one.** [68]
- **Use of oral contraceptives**. The regular and consistent use of condoms offers 70% protection against HPV infection. [69],[70]

2.5.4. Prevention

Currently, there is no way to detect HPV. This is why is so important to know the preventive measures to take against HPV infection. To lower the chances of getting HPV one can:

- **Abstinence from any sexual contact.** It is the only 100% effective way.
- **Use condoms in every sexual activity.** Condoms may not fully protect against getting HPV because the virus can infect not covered areas. [58]
- **Have sex only with someone that only has sex with you**. [58]
- **Screening.** Early detections can prevent cancer. Pap tests, or smear, are one of the most reliable cancer-screening tests available for women. These tests can detect abnormal cells and precancerous changes on the cervix. [58]
- **Get vaccinated.** Vaccine helps get prevented against certain HPV types and HPV related diseases. This topic will be discussed and further explained in the next chapter. [58]

2.5.5. Human papillomavirus vaccination

Human papillomavirus vaccines are vaccines that prevent infection by certain types of HPV. Three different vaccines, which vary in the number of HPV types they protect against, have become available since 2006. In 2006 the first HPV vaccine, a quadrivalent vaccine, was approved. [71] It is targeted against HPV types 16 and 18, which cause approximately 70% of all cervical cancers, and HPV 6 and

11, that cause 90% of anogenital warts. It is recommended for both men and women aged between 9 and 26. [72]

A bivalent vaccine, which protects against types 16 and 18, is being commercialized in Portugal since October 2007.It is approved for girls and women aged 9 to 25. [73]

Both vaccines have the same dose schedule: 2-dose series (0, 6-12 month schedule) if they are younger than 15 and 3-dose schedule (0, 1–2, 6 month schedule) if they are older than 15. [58]

The 10th of July of 2015, the European Medicines Agency (EMA) granted a marketing authorization for a new vaccine, which prevents against five additional high-risk HPV types. It is targeted against HPV 6, 11, 16, 18, 31, 45, 52, 58. The 9 types of HPV that the nonavalent vaccine protects are responsible for approximately 90% of all cases of cervical cancer, 85-90% of cancers in the vulva, 90-95% of cancers of the anus and 80-85% of cancers of the vagina, associated with HPV. [74]

Figure 6. Vaccination statics. [59]

2.5.5.1 HPV vaccination in Portugal and Spain

Since October 2008, the quadrivalent vaccine was in the National Vaccination Program for girls aged 13 in a three-dose schedule (0, 6 and 6 months). The 1st of October of 2014, the vaccine was recommended to all girls aged between 10 and 13 in a two-dose schedule (0 and 6 months). The 1st of January of 2017, the quadrivalent vaccine was replaced by the nonavalent vaccine. [74]

In Spain, the vaccine has been in the vaccination program since 2008 for girls aged 11. In the current scholar course 2017- 2018 the new nonavalent vaccine was the one in the vaccination program for girls. [75]

2.5.5.2. The vaccine.

The HPV vaccines produce a higher immune response in preteens and young teens, this is why the Centers for Disease Control and Prevention (CDC) recommends HPV vaccination for children at age 11 or 12. The vaccine is indicated for both males and females 9 through 26 years old to help prevent against diseases caused by certain types of HPV, [59] the schedule to follow is represented the following table:

Age	Nº of doses	Schedule	Minimum interval between doses
9- 14 years	2 doses	1st shot: Today 2nd shot: 6-12 months after the first shot	5 months
	3 doses	1st shot: Today 2nd shot: 2 months after the first shot. 3rd shot: 6 months after the first shot	1 months between the first and second dose 3 months between the second and third dose
≥ 15 years	3 doses	1st shot: Today 2nd shot: 2 months after the first shot. 3rd shot: 6 months after the first shot	

Table 5. Vaccination schedule. [73]

The vaccine should be administered intramuscularly in the deltoid region of the upper arm or in the higher anterolateral area of the thigh. [76]

Anyone who is allergic to the ingredients of the vaccine, including those severely allergic to yeast, should not receive the vaccine. Patients with moderate or severe acute illnesses should wait until the illness improves before getting vaccinated. [59], [76]

The HPV vaccine is safe. Most people who get vaccinated don't have any problems with it. Thus far, no serious side effects have been shown to be caused by the vaccines. [76] The most common (≥10%) local and systemic adverse reactions reported are:

Reactions in the arm where the shot is given	Pain (about 8 out of 10)
	Redness or swelling (about 1 person in 4)
Fever	Mild (37,8 º C) (about 1 person in 10)
	Moderate (38,9 ºC) (about 1 person in 65)
Other problems	Headache (up to 1 out of 3)
	Brief fainting and related symptoms

Table 6. Most common side effects of the vaccine [77]

Some other possible side effects include itching, bruising, bleeding, a lump where the shot was given, nausea, dizziness, tiredness, diarrhea, abdominal pain, and sore throat. [59]

Fainting can happen after being vaccinated as with any other vaccine. Falls after fainting may sometimes lead to serious injuries. For this reason, the health care professional may ask to sit or lie down for 15 minutes after getting the vaccine. [59]

HPV vaccines are highly effective in providing protection against the HPV types they are target when given before initial exposure to the virus. If one already has an HPV infection, getting an HPV vaccine can't treat it. What it can do is protect from getting other types of HPV. It does not protect from a disease

that is caused by other types of HPV, other viruses or bacteria. Studies estimate that the use of the nonavalent vaccine offers a 90% of protection against vaccine and a 74% HPV- associated cancers. [78], [79]

Research studies show that there is no evidence of weakened protection over time, the vaccine should protect for at least ten years. [59]

The price of the vaccine, for the 3 doses, is approximately 300 euros and it is sell in the pharmacies. [80]

2.5.6. Human papillomavirus vaccination in men

Although HPV is currently responsible for approximately 50% of penile cancer, 90% of anal cancer and 35% of oropharyngeal cancer worldwide, the average annual incidences of these cancers are low in comparison to cervical cancer. [62], [81] This is why HPV has always been strongly linked with cervical cancer and with a greater exposure in media targeted to women. The vaccination programs with HPV vaccine only for girls, prove that statement.

The use of 'female-only' vaccination programs may imply some type of immunity to the male population because the burden of HPV sexually active individuals is reduced, which provides some protection to men from HPV-related health problems. Nevertheless, this type of approach has some drawbacks. Firstly, while providing some protection to the male population, it will not be as completed as if it was targeted to both sexes. Secondly, the vaccination of both sexes would avoid the stigmatization of HPV as a female-only issue in the general population. Finally, this vaccination plan does not provide immunity to men who have sex with men (MSM), which are at higher risk of developing anal cancer as a consequence of HPV exposure [82]

As this thesis aims to help the medical community in understanding men's views regarding HPV vaccination, different studies concerning HPV knowledge, awareness and attitude towards the vaccine were analyzed in order to perform a better design of the new method.
Different studies show that HPV knowledge and awareness is generally poor, being it usually greater among the female population. [3], [83], [84], [85], [86], [87]

HPV vaccines acceptance is influenced by patient, parent and provider attitudes against the vaccine. Ethnicity, socio-demographic and psychosocial factors can also have an important role in this decision. Characteristics such as age, perceived access to the vaccine, societal norms, religious background and perceptions about disease severity and susceptibility may influence the uptake of these vaccines. Broadly speaking, barriers to a vaccine can be logistical and/or cognitive. [2], [88]

The acceptance of HPV vaccine among heterosexual men is lower than the reported for gay and bisexual men. This may be because HPV vaccine may be particularly attractive to this community, who the risk of anal cancer is about seventeen times higher in sexually active gay and bisexual men than in men who have sex only with women. [89], [90]

Concern about aversion to injections and fear of needles and having to have three doses, side effects and vaccine safety are associated with HPV vaccine refusal in men population. Dislike and distrust of vaccinations may also be perceived as barriers. [91]

Some questionnaires have been conducted and men could express their favorable opinion, some of those include wanting to take the vaccine for a desire to stay healthy, for prevention of cancer in their sexual partner(s), for prevention of their own cancers, for fear of cancer and for prevention of genital warts. On the other hand, the main reasons they stated for not wanting the vaccine include a monogamous relationship and not being at risk and not enough evidence yet to prove that it will help men. [83], [88]
Logistical obstacles to HPV vaccination include the complexities of access to service, the requirement for multiple vaccine doses and vaccine cost, especially for men ≤26 years with fewer financial resources [88], [92]

It has been proved that the ones doubting, call for information about HPV related disease and HPV vaccination. The ones that reject the vaccine are more concerned about vaccines and side effects. They listen less to the physician and more to family and social media. [2]

Some MSM associated the vaccine with promiscuity and expressed concerns about being stigmatized if they were to accept the HPV vaccination. [91]

It is important to mention once again the environment's influence, the acceptance had proved to be higher if the males believe that their parents, partners, friends or physicians would encourage them to receive the vaccine. [62] Thus, the role of the health care provider is essential in vaccination acceptance, the education of HCPs about HPV and their support/recommendation is particularly crucial if the vaccine wants to reach a society status of "Gender Neutral Vaccine". [2], [83], [93]

2.6. Summary. Placing the new method.

It is important to bear in mind that for this new method, the shared decision making is not in a one-to-one context. It is placed in the patient side and it is targeting a whole community due to the nature of the vaccinations plans and its final impact. We suggest a tentative name for the new method of community-shared decision making.
The literature existence related to this concept is practically null. However, the basic grounds can be obtained from the literature reviewed and this is the reason why they were taken into account.

2.6.1. Shared decision making

Broadly, this method aims to elicit the community decision. To arrive to this decision, each patient shares their opinion, views and concerns until a consensus among them is reached. The steps this method need to follow are ones of the SDM, as they are the basics steps for any decision context. Patients are invited to participate, they are presented with the options and information of benefits and risk, options are evaluated based on patient's concerns, a deliberation and decision making is facilitated to later the doctor assist with implementation. [4] It is in the deliberation stage where, instead of deliberating with a doctor, they must discuss it between the patient's community.

2.6.2. Decision aids

As seen in literature, the topic of using personal experiences is being under discussion and study. This is because the influence of other's opinion has been proven to influence their own decision. This is an essential topic for this new method because prevention actions like vaccination would need for the involvement of a community to be effective, it should also allow for interaction between the participants, but currently there are no PDA that allow it.
For the decision to happen, they need to be presented with a balanced information about each option, risks and benefits. This information is handed at the beginning of the process. This new method needs to follow the definition of PDA as "*interventions designed to help people make specific, deliberative choices. They make explicit the decision, providing information on the options and outcomes that are relevant to a patient's health status, and clarify personal values. They are intended as adjuncts to counseling.*" [20] as it has to help students know in sufficient detail the options under consideration for the decision.

The new method needed can be considered as the simplest patient decision aid tool, because it presents electronically all the information need to make the decision.

2.6.3. Participatory methods

The communication among participants is done by a participatory approach. They will discuss the assessment of weights to obtain a final decision on the problem. It will follow the same guidelines as any process.

After revising the main participatory methods, the one that fits better the objectives is the Delphi method. This is the one chosen to be implemented in the study case because its four key features. By using questionnaires, the process is anonymous and can be held on-line, which will facilitate the dissemination of it and target a bigger group, by using questionnaires. The iteration and controlled feedback are the features allowing for communication among male students and, finally, with the statistical aggregation of group response the medical community can be informed about their opinions and beliefs as a community.

2.6.4. MCDA

To elicit a patient community decision, a MCDA method will be used. Using the participatory approach, they will assess weights to the criteria and share their opinions. Once a consensus is obtained, it just has to follow a usual MCDA procedure, the difference here is the way that weights were assessed. The challenge of using it among a community is to try to elicit all the possible criteria of all of them and implement them in the participatory method.

The method used in the MACBETH because it uses a pair-wise comparison by given a qualitative judgment of the difference in attractiveness between each two options. The use of this comprehensive questioning protocol has been the reason why this is the MCDA technique used in this thesis, given that an online platform will be implemented and therefore something that is very clear to be understood by all the participants is needed.

3. Preparation, design and implementation of a new method for community-shared decision making. Case study: HPV vaccination in men

In order to get insights into male university students' beliefs and opinions regarding HPV, a new method that follows a socio technical approach was adhered.
As a socio-technical approach it is needed to combine a MCDA analysis and a participatory method in order to go through all the process. The MCDA used is the MACBETH and the steps needed to build a model will be followed as well as their type of questioning. The participatory method selected is the Delphi method, which will allow the communication among the community, to elicit individual preferences and to analyze how the opinion of others may influence the own views in an anonymous way.

Broadly, the MACBETH steps will be followed in order to elicit a decision. It is in the evaluation section where the participatory method takes part. It will be used for the weighing part of the MCDA.

3.1. Structuring

The structuring part of a MCDA is the starting point to build the model. As seen in the MACBETH chapter, structuring the models consists in define the options and the criteria with their descriptors of performance. The decision is whether male would be willing to get vaccinated or not. It is a decision with just two possible options:

- Get vaccinated.
- Not get vaccinated.

This decision depends on the patient. It's influenced by the different patient's opinions regarding different criterion that might be taken into account and how they value them.

At this step, the criteria that could influence the decision should be identified. In order to do that it was necessary a revision to the literature review regarding HPV vaccination in men and to the different studies carried out that expose their views and concerns. Once it was done, the most remarkable and repeated thoughts could be identified as the following:

- **COST:** the price of all the vaccine's doses.
- **SIDE EFFECTS:** there might be some side effects if the patient gets the vaccine.
- **EFFICACY FOR WARTS:** It might be important to take into account the efficacy's percentage of the vaccine to be protected against warts.
- **EFFICACY FOR CANCER.**: It might be important to take into account the efficacy's percentage of the vaccine to be protected against cancer.

- **TIME/ACCESSABILITY:** The time spent in getting all the vaccines and being under the treatment.
- **RELIGIOUS OR CULTURAL BELIEFS:**
    - Their religion might be against vaccination.
    - Their religion might be against sex before marriage and divorce → only one sexual partner.
    - Abstinence
    - Fear of needles.
    - Personal opinion about vaccination. (ie: homeopathy, be against them…)
- **LIFESTYLE:** Here we can include:
    - The sexual activity of the patient.
    - Sexual orientation

When looking at this list, a general classification could be done by dividing it into aspects directly related with the vaccine and aspects related with the patient.

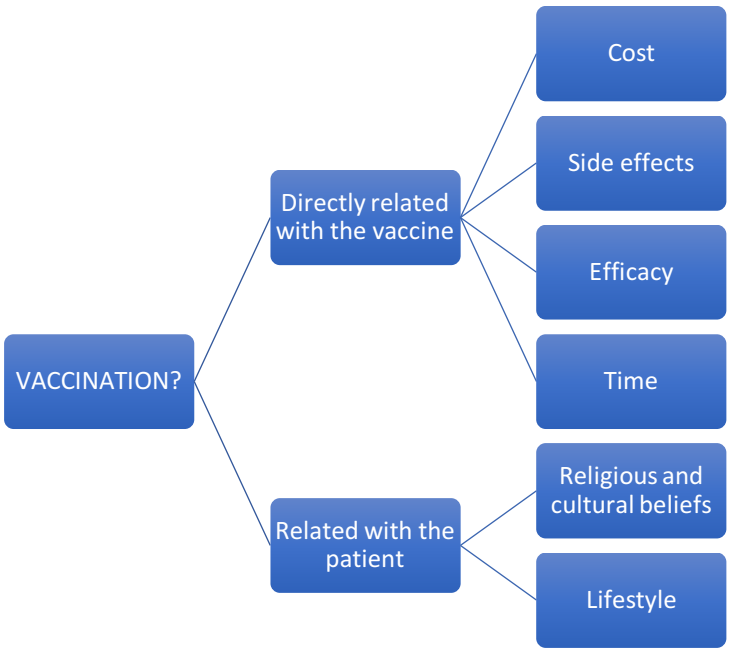

Figure 7. Organization of different criteria of getting the vaccine or not.

The aspects related with the patient will not be taking into account for the model. Although they would obviously influence the decision, this method is pretended to be launch on a large, unknown population and these aspects are not equal for all the population nor objective.

It would be important to ask for the personal features (variables of control) outside the model to see how and at which degree they affect the decision. Look into the weights in view of this and not condition the model to this.

The objective criteria related with the vaccine- the one future included in the model- were validated with an expert in the field, a pediatrician. A power point presentation was made explaining to her what properties should a criterion have in order to be approved. The criteria should: [48], [49]

- Be complete (exhaustive): describe all of the important consequences of the options.
- Be non-redundant: does not describe overlapping consequences of the options
- Be concise: can adequately describe only the important consequences of the options
- Be decomposable (from the independence property of each criterion)
- Be consensual (from the intelligibility and consensually properties of each criterion)
- Be understandable (Intelligible): helps any interested individual to envisage all of the important consequences

She was also asked for other criteria that could be used as well as for the main concerns of the boys according to her medical encounters that can condition the answer.

The criteria included in the model is the one that follows:

Criteria	Descriptor of performance	Type of descriptor	Levels
Cost	Amount of money in euros.	Quantitative/ Direct	• 0 euros • 300 euros
Efficacy for all HPV related cancers	Percentage of the efficacy	Quantitative/Direct	• 0% efficacy • 74% efficacy
Efficacy for warts	Percentage of the efficacy	Quantitative/Direct	• 0% efficacy • 90% efficacy
Side effects	Explanation of the side effects	Qualitative/Direct	• No side effects • Pain, redness, swelling, fever, headache…
Time	Amount of time one should spent under the treatment in months	Quantitative/Direct	• 0 months • 6 months

Table 7. Definition of the descriptors of performance.

3.2. Evaluation.

This model is formed by two options (vaccine or not) which means the value function would not be needed. The options are compared directly. The method should ask for weighting only. People should weight the five criteria (cost, efficacy for warts, efficacy for all HPV related cancers, side effects and time). For these criteria, each one is better under one option (scoring 100) and for the other option is just the opposite (scoring 0).

At this point, one of the most important parts of the thesis as well as one of the most difficult is faced. The questioning protocol for weighting criteria needs to be established. The question should be simple in order to be understood because the process is held on-line as a non-face to face method, which always complicates the communication and the intelligibility of everything involved.

Another requirement that the question needs to accomplish is to not fall into “the most common critical mistake”. This is weighing criteria based only on the notion of importance. The question should be based on improvements, not only in the criteria. For instance, the fact that the weight of ‘‘Criteria A’’ is the double of the weight of ‘‘Criteria B’’ means, that an improvement of performance from the low reference level to the upper reference level in ‘‘Criteria A’’ is viewed as twice as attractive than a similar improvement in the ‘‘Criteria B’’ criterion. As this statement is only valid for the specific references levels defined, stating the “Criteria A” is twice as important as “Criteria B”. [57]

As this problematic affects all the community and this thesis is treated under the basis of a community-shared decision making, this question should be implemented in a Delphi process. In order to see how affects the opinion of the other students to their own.

Welphi is an online questionnaire platform that implements the Delphi method. Thus, the application will allow the creation the questionnaire in order to obtain the opinions of the participants, dispersed geographically, in an easy and accessible way. At the beginning of each round, the platform automatically sends invitation emails. During each round, it is possible to send reminders to those who have not yet completed the questionnaire, promoting participation. [95]

3.2.1. Preparation

In this particular case, the aim is to elicit male patients' views regarding HPV in order to assist the medical community in better understanding them. Bearing the aim in mind, the identification, selection and restriction for inviting participants are:

- Only males are allowed to get involved.
- This a community problematic. It is needed to engage as many participants as possible in order to capture all the possible different views.
- As the vaccine is recommended for males aged less or equal than 26 years, university male students will be reached be. This way it is ensured that, in its majority, the age requirement is accomplished and it is possible to contact a large number of students through the existing channels of communication.

As Welphi platform requires the input of participants' emails before the process starts, the first step was to collect the emails. During the acquisition of emails, the problematic of gathering some of them from Portuguese students was presented. In order to face it, *Núcleo de Engenharia Biomédica*, as the entity who has a mailing list with all the biomedical students, was contacted and asked if they could help somehow. The solution given, stated to be the easiest and the most functional way to get answers, was that they send an email with a link to a google form attached where students could introduce their emails.

As the Welphi platform is only designed for the Delphi method being implemented, the variables of control needed to be asked in a different platform. The google form used to gather the emails can serve as well to collect the participants' personal information.

After a revision of the bibliographic review regarding HPV and HPV vaccination, the main ideas need to be selected. A summary of the information will be highlighted in this first screen of the Welphi platform. The information presented should be clear, easy to understand and not too long. The fact of the sentences being short always helps in these situations.

3.2.2. Design and implementation

The procedure followed in order to implement the process will be explained in this sub-chapter will as it was presented to participants.

3.2.2.1. Invitation of the participants

The email sent had to be something catchy, clear and not very long to get as many answers as possible. However, there were some ideas that needed to be included:

- Present the topic
- Explain the aim of the study
- Emphasize in the anonymity of the answers and the amount of time that it will take.
- Mention that is for a thesis

The use of questions in the text is highly recommended to engage people to keep reading which may lead to more possible participants.
In order to not make the email too long the explanation of the next steps, the Delphi questionnaire, were presented in the google form.

The text they got was the following:

Title: Action towards Human Papillomavirus (HPV) infection.

Did you know that nearly all sexually active people get HPV infection at some point in their lives? And that some types of HPV cause warts and cancer?

Don't worry if it doesn't sound familiar to you and there's no need for panic because there is a vaccine to help to prevent the infection.

To assist the medical community in better understanding the views of male university students regarding this important health question, we have devised a participatory process to collect your opinions regarding HPV vaccination.

This project is being conducted under a biomedical engineering master thesis; if you have any interest in being involved, please follow this link: https://goo.gl/forms/KNUaKfYnj0jxbTUK2

The questionnaires will not take you more than 5 minutes to answer and all the answers will be treated anonymously.

Thank you very much for your participation!

Judith Coll Rubio

3.2.2.2. Google form.

It was composed of nine questions, only three of them compulsory: email, age and nationality. The other six, as they were quite personal, were optional. Additionally of asking for some variables of control, some other questions were proposed. The expert supervising the study had an interest in knowing if the participants have a family doctor or if they had been vaccinated. The fact of knowing the percentage of the participants that had notion about HPV was also asked.

Although the first idea was to deliver it together it with the second round of the process, because this way they would had received the information needed to understand HPV and asking if they were more willing to vaccinate could have been possible, it was worth to change it to get more emails and, therefore, more possible participants.

The Google form was disseminated the 12th of October. It got 80 responses. Other 27 were invited to participate, because their emails were collected before launching the google form, but didn't answer.

HPV Vaccination in men

We need to collect your views regarding this important health question.
This will be done with the support of a three-round Delphi process, to be held on-line. The first round will start next week and aims to collect your views regarding the importance of the implications of the vaccine. In the second and third round we will then be faced with the views of your fellow colleagues and be invited to either keep or change your previous judgments.
In the beginning of the first round you will be presented with a summary of all the information needed regarding HPV infection.
The questionnaires will not take you more than 5 minutes and they are completely anonymous. If you have any doubt, please contact with: judithcoru@gmail.com
Thank you.

*Required

1. **Email address** *

_____

2. **Age** *

_____

3. **Nationality** *
Mark only one oval.

- ◯ Portuguese
- ◯ Spanish
- ◯ Other: _____

4. **Do you have a stable relationship?**
Mark only one oval.

- ◯ Yes
- ◯ No

5. **Sexual Orientation**
Mark only one oval.

- ◯ Heterosexual
- ◯ Homosexual
- ◯ Bisexual
- ◯ Other: _____

6. **Do you have any issue with vaccines?**
Tick all that apply.

- ☐ Yes. I have fear of needles.
- ☐ Yes. I don't believe in them.
- ☐ No.
- ☐ Other: _____

7. **Do you have a family doctor?**
Mark only one oval.

- ◯ Yes
- ◯ No
- ◯ Other: _____

8. **Have you been vaccinated for HPV?**
Mark only one oval.

- ◯ Yes
- ◯ No
- ◯ Started, but did not conclude the vaccination plan

9. **Did you know anything about how HPV affects men before this questionnaire?**
Mark only one oval.

- ◯ Yes
- ◯ No

Figure 8. Google form questions.

3.2.2.3. Welphi platform

The types of rounds involved in this process are closed. Three rounds would be ideal, however due to time restrains and the fact that this was an exploratory study, only two rounds were conducted.
Feedback was provided at the end of the process. Participants received a thank you email with a table that summarizes the final answers. This email will also be used to ask additional question that couldn't be inserted in the google form.
It will be considered that the level of agreement is reached when it is more than 51%.
A week was established as adequate for the duration if each round.

3.2.2.3.1. Questioning protocol

After discussing and testing different types of questioning protocols with a random group of people unconnected with the thesis, the type of question that was decided to tackle was to ask how important was for them to move from the worst option in each criterion to the best one and to confront them with the performance levels. (see Figure 10)
Thus, they will be presented with 5 criteria regarding the different implications that taking or not the vaccine has and asked how much they value them, according to their willingness to be prevented of HPV infection.
The criteria will be presented alphabetically in order to no introduce any kind of preference or bias.
The scale used to qualitative judge the criteria is the same on as the MACBETH uses with 7 different levels from *"not"* to "*extreme".* There might be some questions to which the respondents may not know to answer or not want to. As a way of preventing the abandonment of the process or answering randomly, the option "do not know/do not want to answer" was also included. The reason of selecting this option can vary largely is this is why they can also provide comments.

3.2.2.3.2. Round 1

Once the gathering of emails finished and all the 107 were introduced in the platform, the participants receive an email with an invitation to participate in the process. They can access to it once they had registered. Once they are in the platform, the round can be divided in 3 different screens (welcome message, the question and thank you message).
In the first screen, they will find the welcome message. Here is where they have to find an explanation about what they will find in the following screen, how to answer the question and all the information needed to correctly make the judgements. They were presented with the following summary of all the information needed regarding HPV infection and how the questionnaire works.

Welcome to this Delphi questionnaire that **aims to collect your views regarding Human Papillomavirus (HPV) vaccination.**

It won't take longer than 5 minutes.

You will be presented with 5 criteria regarding the different implications that taking or not the vaccine has and **will be asked the following question:**

> *"Imagine yourself in face of a treatment to prevent against HPV virus, warts and cancer. The treatment consists of: a vaccination plan of 6 months, a cost of 300 euros, an efficacy for warts of 90% and for cancer of 78% and possible side effects. How important is for you to…"*

For each individual criterion, you will answer to the questions using a qualitative scale from "Very weakly important" to "Extremely Important" and while answering you should consider how much do you value the different implications that taking or not the vaccine have, according to your willingness to be prevented of HPV infection. For each criteria you can also answer "Don't know / Don't want to answer"and provide comments.

You will have 4 days (until Sunday 22nd at midnight) to submit your answers.

Before starting, there are a few things you need to know about HPV.

INFORMATION ABOUT HPV

- Infection with HPV is the most common sexually transmitted disease worldwide. It is transmitted by skin-to-skin contact.
- There are more than a hundred types of HPV. Most HPV infections don't cause any symptoms and can go away on their own, but others can cause health problems.
- The ones that cause health problems are known to cause the majority of HPV-related cancer and diseases.
    - LOW RISK TYPES can cause anogenital warts.
    - HIGH RISK TYPES are responsible for HPV related cancer:
        - → Penile cancer;
        - → Anal cancer;
        - → Cancers in the throat, including the base of the tongue and tonsils (oropharynx). Oropharyngeal cancer is 3 to 5 times more common in men.
- Risk factors:
    - Multiple sexual partners;
    - Be a non-circumcised man or being with one;
    - Smoke;
    - Immunosuppression and HIV infection;
    - Not using condoms.

INFORMATION ABOUT THE VACCINE

- Vaccination protects against certain HPV-related cancers and diseases, when given before there is any contact with the virus.
- The vaccine prevents 90% of genital warts and 74% of all HPV cancers.
- The vaccine is not a treatment for external genital lesions or cancers.

- For individuals between 15 and 26 years of age, it is administered using a 3-dose schedule at 0, 2 and 6 months.
- The vaccine is expected to provide protection for at least 10 years.
- The vaccine should be administered intramuscularly in the deltoid region of the upper arm or in the higher anterolateral area of the thigh.
- People should not get it if they have or have had an allergic reaction to:
    - A previous dose of the vaccine;
    - Any component of the vaccine (including allergy to yeast).
- The HPV vaccine is safe. Most people who get vaccinated don't have any problems with it. The most common side effects are:

Reactions in the arm where the shot is given	**Pain (about 8 out of 10)**
	Redness or swelling (about 1 person in 4)
Fever	**Mild (37,8 º C) (about 1 person in 10)**
	Moderate (38,9 ºC) (about 1 person in 65)
Other problems	**Headache (up to 1 out of 3)**
	Brief fainting and related symptoms

What is the way to get it?

You need to get an appointment with the doctor and he or she will give you a prescription. With it you just have to go to the pharmacy to buy for approximately 300 euros and then go to the health care center to get vaccinated.

Figure 9. Welcome message round 1

The next screen was the question

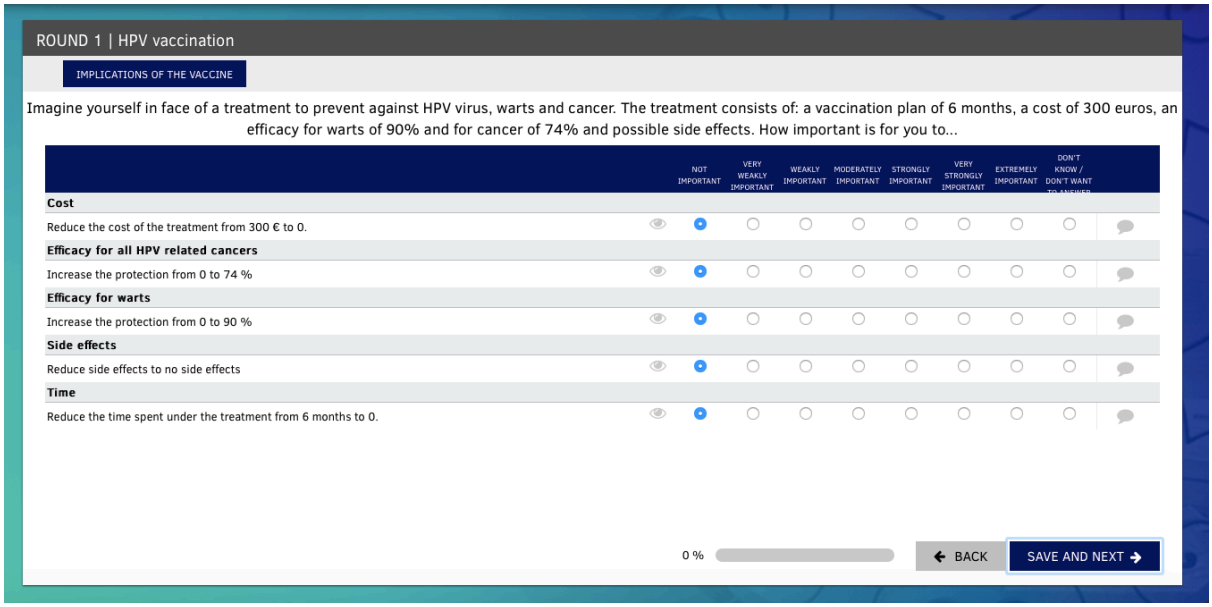

Figure 10. Question. Round 1

Once the question was answered for the five criteria, the first round was over.

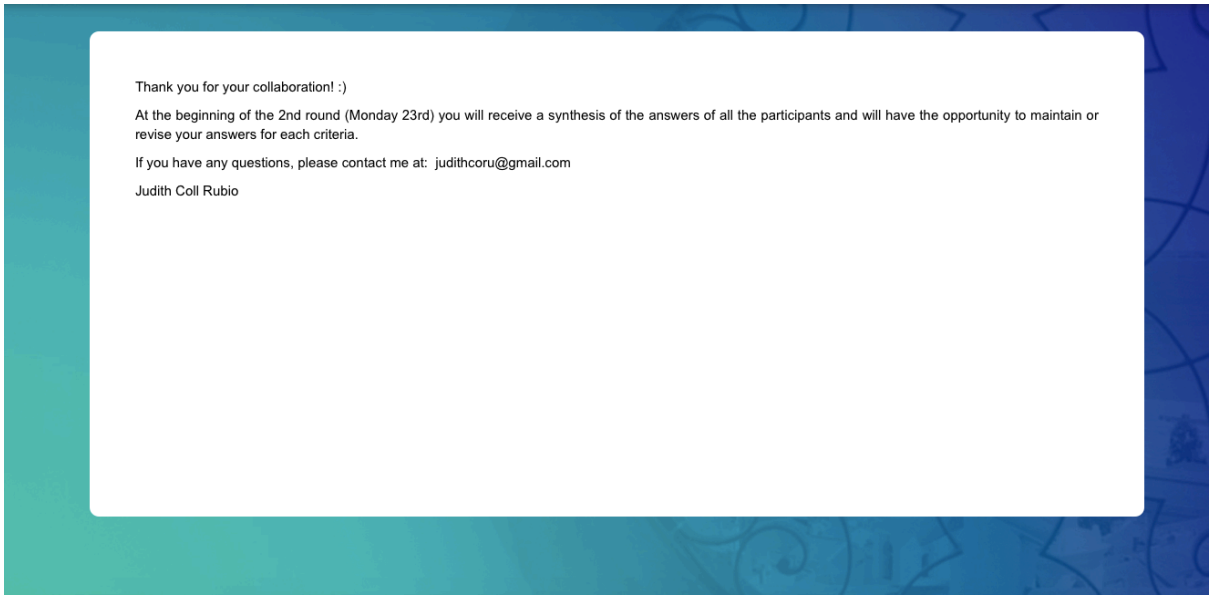

Figure 11. Thank you message. Round 1

The Welphi questionnaire was send to 107 participants, 46 of them (43%) went through round 1 between 18th of October and 24th of October. The 22nd of October a last reminder to participate in the process was sent.

3.2.2.3.3. Round 2.

The participants who completed the first round were invited to continue the process and complete the second and last round. The procedure was the same: an email from the platform was send, notifying them the second round was open. When they logged in, they were informed of what did the second round consist of.

Welcome to "HPV Vaccination in men"- second round.

Thank you for your participation in the first round of this Delphi process. Your involvement is crucial for the success of this project.

In this second round, you will access the same list of five criteria as in the previous round. Together with this information you will now access an anonymous summary of all answers of the participants in the first round, as well as their comments. Your previous answers will be highlighted. In this second round, for each criterion, you will have the opportunity to either maintain or revise your previous answers.

If you want to maintain your answers please click the button. "Maintain answers and go to next area", this is mandatory to complete the second round.

If you want to revise your answers, please click the button "Change some answers"

In both situations, you will have the opportunity to provide comments associated with your answers. The option "Don't know/Don't want to answer" will still be available.

You will have until the end of the week to submit your answers. In case you have any doubts or questions, please contact: judithcoru@gmail.com

Figure 12. Welcome message round 2

They were faced with the same question together with the views of their fellow colleagues and were invited to either keep or change your previous judgments.

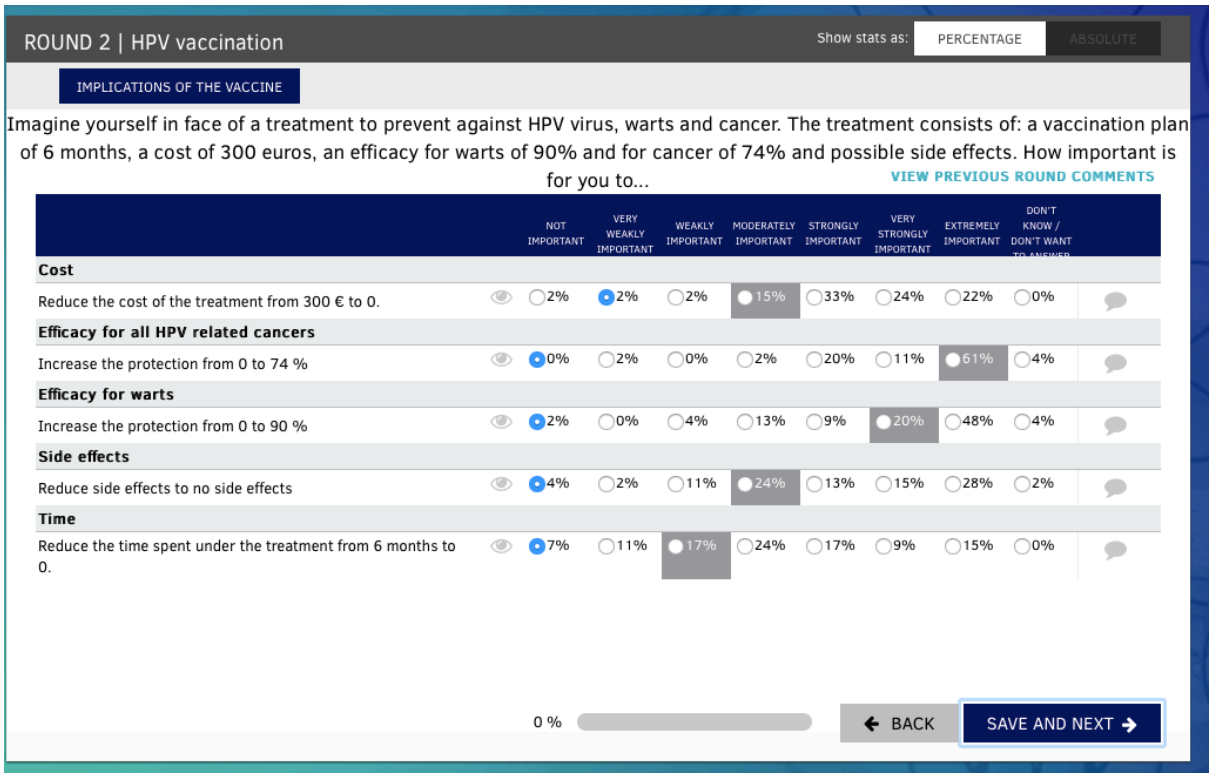

Figure 13. Question round 2

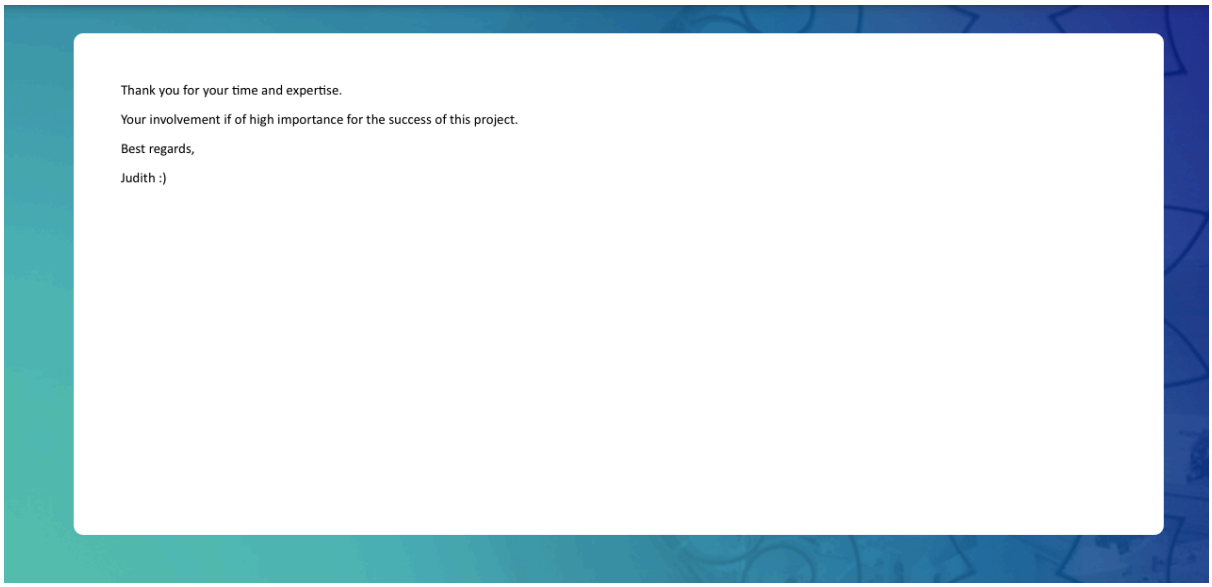

Figure 14. Thank you message round 2.

It started the 24th of October and was available up until 31st of October 27 of them completed the second round (60% of the ones who passed the first round). The 28th of October a first reminder was send, the 30th they received the last reminder.

3.2.2.3.4. Final report email and last question.

At the end of round 2, an email was sent to the participants showing gratitude for the collaboration presenting the final feedback.

Dear participant,

Thank you very much for your participation in this Welphi process. It was crucial!

Below you will find a table with a summary of the final answers of the process.

I'd like to ask you one last question:

Do you think that after being involved in this study your views regarding HPV vaccination in men has changed? Will you be more willing to get vaccinated against HPV?

You can answer it by emailing me at Judithcoru@gmail.com, being the subject of the email a *yes* or a *no*.

Again, thank you very much, I really appreciate your involvement!

	NOT IMPORTANT	VERY WEAKLY IMPORTANT	WEAKLY IMPORTANT	MODERATELY IMPORTANT	STRONGLY IMPORTANT	VERY STRONGLY IMPORTANT	EXTREMELY IMPORTANT	DON'T KNOW / DON'T WANT TO ANSWER
Cost								
Reduce the cost of the treatment from 300 € to 0.		4%		15%	44%	22%	15%	
Efficacy for all HPV related cancers								
Increase the protection from 0 to 74 %					15%	7%	74%	4%
Efficacy for warts								
Increase the protection from 0 to 90 %					11%	11%	74%	4%
Side effects								
Reduce side effects to no side effects	4%		11%	26%	22%	15%	22%	
Time								
Reduce the time spent under the treatment from 6 months to 0.	7%	7%	22%	33%	15%	4%	11%	

Judith Coll Rubio

Figure 15. Thank you email. Feedback and last question.

4. Results and discussion

In this chapter, the results will be presented along with their discussion.

4.1. Google form

As the decision of sending first the google form was made during the gathering of emails, not everyone that answered the google form completed the both rounds of the Delphi and not all who completed both rounds answered the google form.
As the purpose of the questionnaire was to analyze how and at which degree the variables of control affect the decision, only the answers from the ones that completed the process were taken into account. From the group of 27 participants that went through both rounds, the statistical data of 21 of them was also available, because they also participated in the google form.
Hence, the following statistic characterization -of 21/27 students- who completed both rounds, were obtained:

- The mean age is 22,9 years old.
- 60 % of respondents are Spanish, followed by Portuguese, Italian and Argentinian, in this order.
- 67% of them don't have a stable relationship.
- The 90% are heterosexual.
- Most of them (95%) don't have any issue with vaccines.
- Regarding if they have a family doctor, half of them have it and the other half don't.
- Only 15 % have been vaccinated against HPV.
- 71% stated to know nothing about how HPV affects man.

For each one of the questions individually, a graphical representation has been made:

The age of students, which the mean in 22,9 due to the big amount of students aged 23, is in the university age range. Participants from each course were engaged in the process, as might be seen in Figure 16. Age was a factor that had been proved to have affect in the decision, younger people were more willing to vaccinate as they are no that close to the end of the recommendation age. [81], [84]

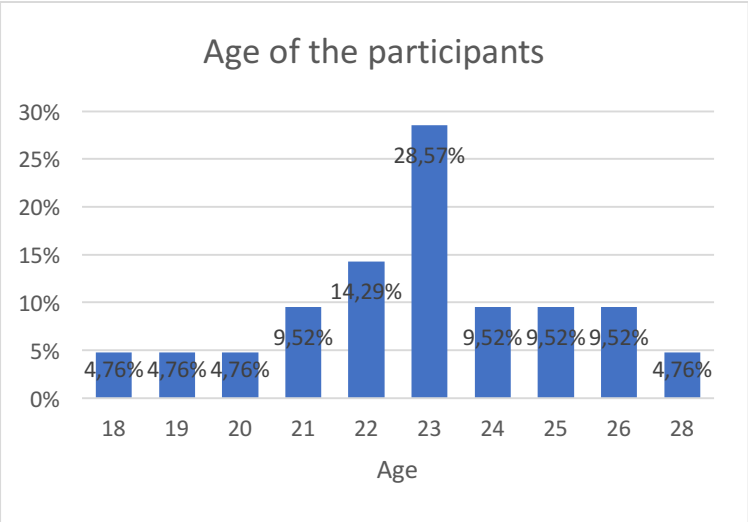

Figure 16. Answers for the age the of participants

Most of the students contacted were from Spain and Portugal, as represented in Figure 17.

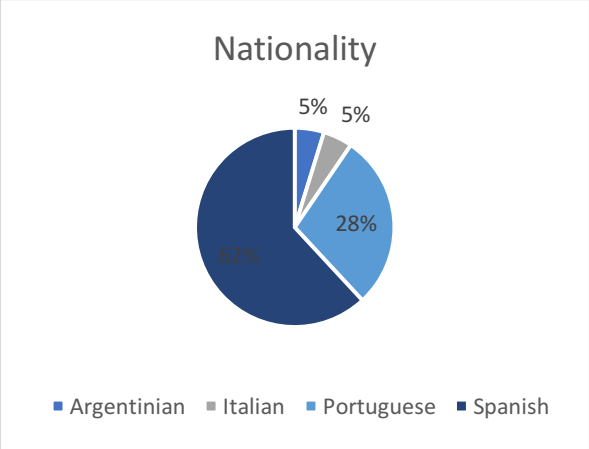

Figure 17. Answers for nationality

Figure 18 shows the percentage of respondents involved in a relationship. This might affect the decision because this affects to their sexual activity.

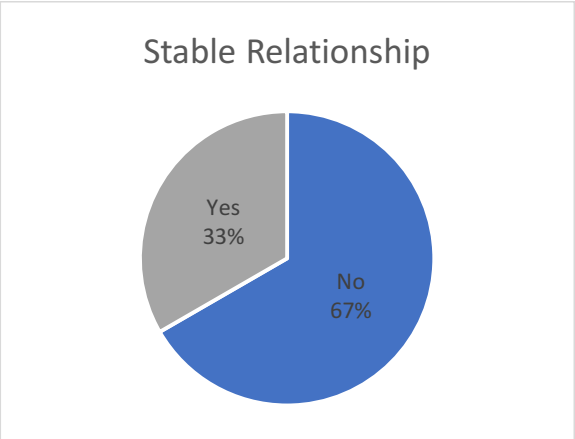

Figure 18. Answers for stable relationship.

In Figure 19 is shown the sexual orientation of the sample. Practically all of them are heterosexual. Given the high influence of HPV infection in gay and bisexual, [82], [90] if there was any relationship between being one and the weights for the criteria wanted to be analyzed.

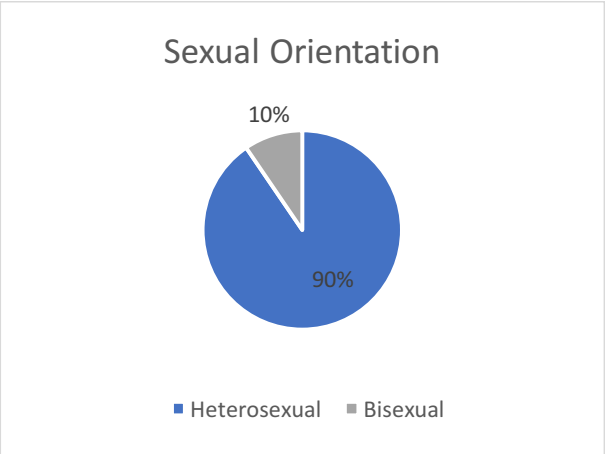

Figure 19. Answers for the sexual orientation of the participants.

Figure 20 shows that for the group studied, the vaccines do not suppose a problem.

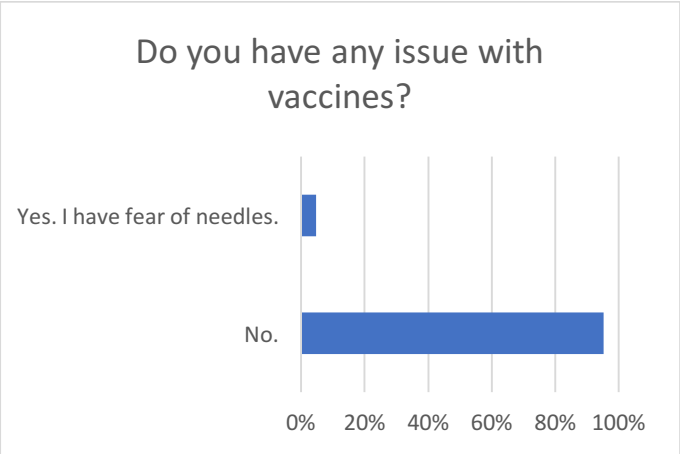

Figure 20. Answers for issues with vaccines.

Half of the cluster have a family doctor while the other half does not.

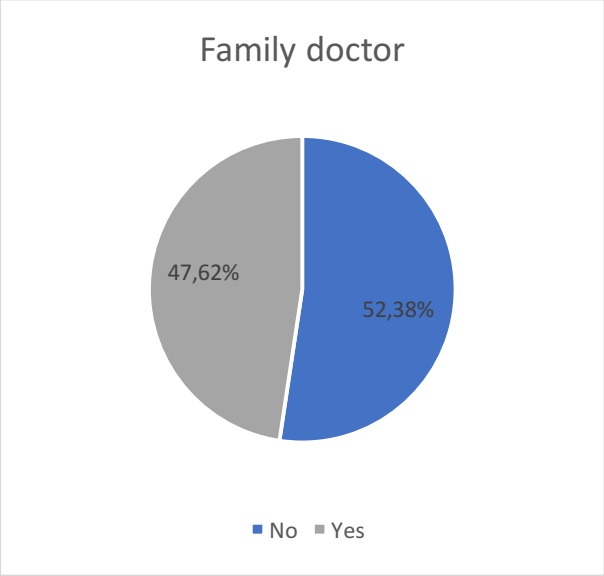

Figure 21. Answers for family doctor.

The distribution of the ones vaccinated and the ones that are not is seen in Figure 22. As expected, the vast majority have not been vaccinated.

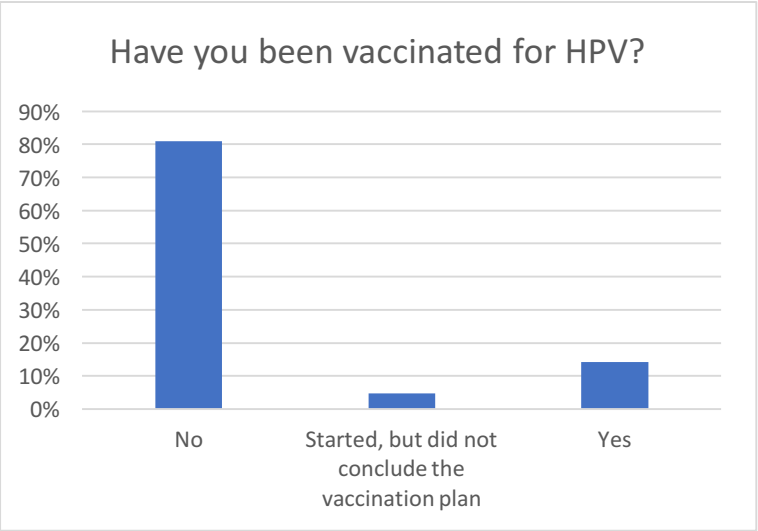

Figure 22. Answers to whether they have been vaccinated or not.

Their answers about if had any knowledge about HPV in men before the questionnaire are represented in Figure 23. This is consistent which seen in the literature review, because a high number of them, the 71%, were not aware of this health issue.

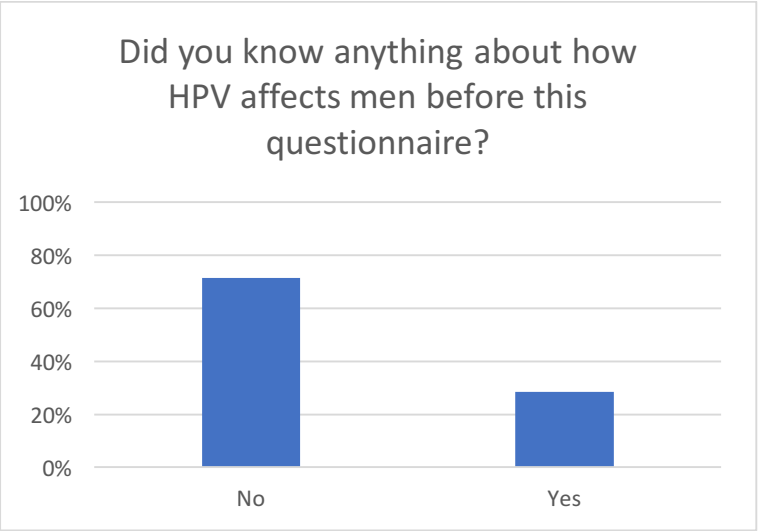

Figure 23. Answers about whether they knew something about VPH or not.

In a way to try to solve the lack of 6 participant's characteristics, to see if these results would have been very different which would suppose significant changes, the data with all the responses was studied. If the starting point is the cluster of all 80 responses. When analyzing just the answers of the participants of interest, the changes are:

- the % of Portuguese participants is bigger now (from 16 % to 28%).
- Everyone that didn't believe in vaccines didn't complete it and people with fear also decreased.
- None of the 6 homosexuals had completed it. And just the 50% of bisexuals.

The other questions didn't have a significant change.

4.2. Round 1.

The results obtained in the first round are shown in Table 8.

	NOT IMP.	V. W. IMP.	W. IMP.	MOD. IMP.	STR. IMP.	V. STR. IMP.	EX. IMP.	DK / D WTA
Cost								
Reduce the cost of the treatment from 300 € to 0.	2%	2%	2%	15%	33%	24%	22%	
Efficacy for all HPV related cancers								
Increase the protection from 0 to 74 %		2%		2%	20%	11%	61%	4%
Efficacy for warts								
Increase the protection from 0 to 90 %	2%		4%	13%	9%	20%	48%	4%
Side effects								
Reduce side effects to no side effects	4%	2%	11%	24%	13%	15%	28%	2%
Time								
Reduce the time spent under the treatment from 6 months to 0.	9%	11%	17%	24%	17%	9%	15%	

Table 8. Results obtained in round 1.

Considering a level of agreement above 51 %, as might be seen, the results are quite dispersed. Only in efficacy for all HPV related cancers this agreement is reached among participants.

The criteria that is most dispersed is time. Some of them found it very important and almost at the same level for others it is not important.

There are three criteria (both efficacies and side effects) to which people do not know how to value. Even after explaining to them, they are not still sure of what to answer.

Although the level of agreement is not reached. It should be noted that if the percentages are aggregated some criteria had been perceived as more important than another. Considering the levels "strongly important", "very strongly important" and "extremely important" the three main concerns of the participants were increase the protection from HPV related cancers, the cost and side effects, respectively.

If this aggregation is also done considering the levels "not important", "very weakly important" and "weakly important" in order to see which criterion have had a less weight, this one is the time.

4.3. Round 2.

Succeeding the closure of round 2, the final results are the ones seen in Table 9

	NOT IMP.	V. W. IMP.	W. IMP.	MOD. IMP.	STR. IMP.	V. STR. IMP.	EX. IMP.	DK / D WTA
Cost								
Reduce the cost of the treatment from 300 € to 0.		4%		15%	44%	22%	15%	
Efficacy for all HPV related cancers								
Increase the protection from 0 to 74 %					15%	7%	74%	4%
Efficacy for warts								
Increase the protection from 0 to 90 %					11%	11%	74%	4%
Side effects								
Reduce side effects to no side effects	4%		11%	26%	22%	15%	22%	
Time								
Reduce the time spent under the treatment from 6 months to 0.	7%	7%	22%	33%	12%	4%	11%	

Table 9. Results at the end of round 2.

Considering a level of agreement of 51%, in this round the answers showed a higher level of agreement. Now both efficacies have reached and surpassed this level. From round one to round two, all participants acknowledged the importance of the vaccine in terms of efficacy. Although, there are still participants who are not sure about the efficacy.

For time participants changed from being important to not important. In side effects, also some changes but cannot lead to any conclusion.

The objective of the Delphi was to allow participants to communicate. It should be influenced by each other's opinions. This communication existed, because there is a lot of opinion changes.

There is one participant who left some comments regarding cost and efficacy. Maybe he was interested in the topic and was seeing that there were no strong agreement and he wanted for people to see his opinion.

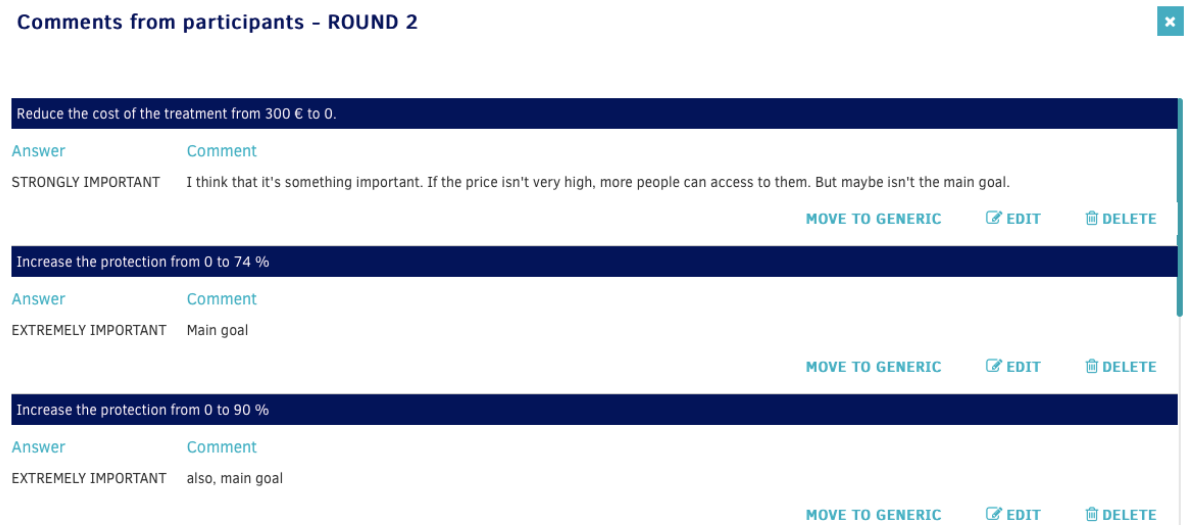

Figure 24. Comments from participants. Round 2.

4.4. Final question

Ask participants if participating in the study changed their attitude, if they were more willing to get vaccinated, was very interesting topic because it would give a first direct general opinion of their decision.

This is why the process concluded asking if they were more willing to vaccinate after being involved. Only 4 of the participants answered 2 of them stated that they weren't more willing to vaccinate after had been involved in the study and the other 2 stated the opposite.

The ratio response was extremely low, the cluster obtained is so small that it is not significant and it should not be taken into account for further analysis.

The low feedback may be because they had already gone through many steps to complete the process in an altruistic way. When they thought that the process was over because the email received was to thank them and give feedback, they were faced again with another question. In order to answer it, they had to take a really active role, by sending an email. Although this was the only plausible way to formulate the last question it was quite utopian, this should have been implemented in the same platform.

4.5. Comparing rounds

The first and the second round will be compared in order to see if there was a change of opinion of some of the participants and lead to a higher level of agreement.

In Figure 25 below one can see what do students think about the implications of the cost.

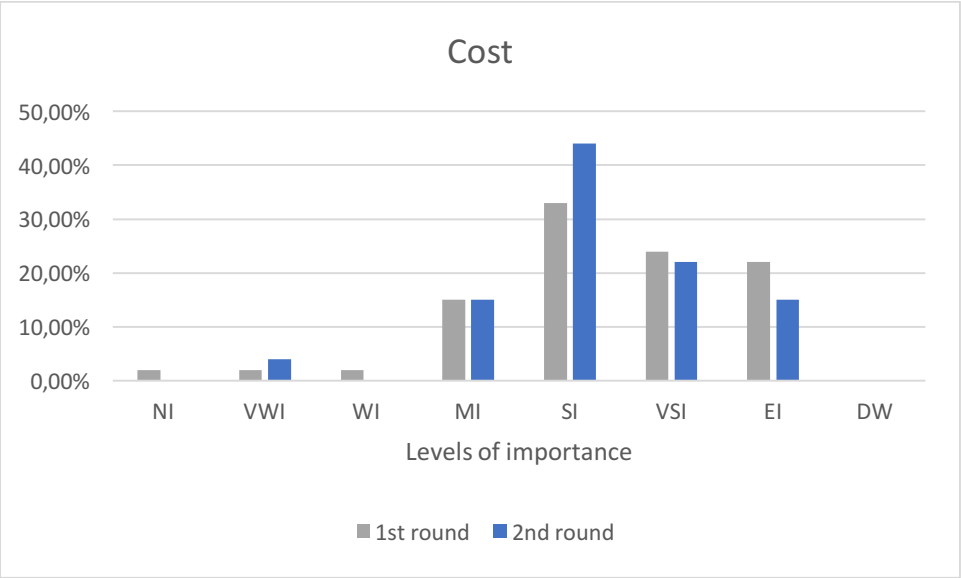

Figure 25. Comparing results for cost.

In both rounds the most popular answer was “Strongly Important” with a higher level of agreement in the second round. But in either of them the level of agreement was reached. It should be mention, however, that if aggregating the percentages of the three categories that give to it a bigger importance, cost is considered as one of the main important implications.

Moving to how they value the efficacy for HPV related cancers (Figure 26), can be seen as it is an important criterion. Practically the 100% is moving between the three semantic categories of bigger importance. More people value it as “extremely important” in the second round, getting a bigger level of agreement.

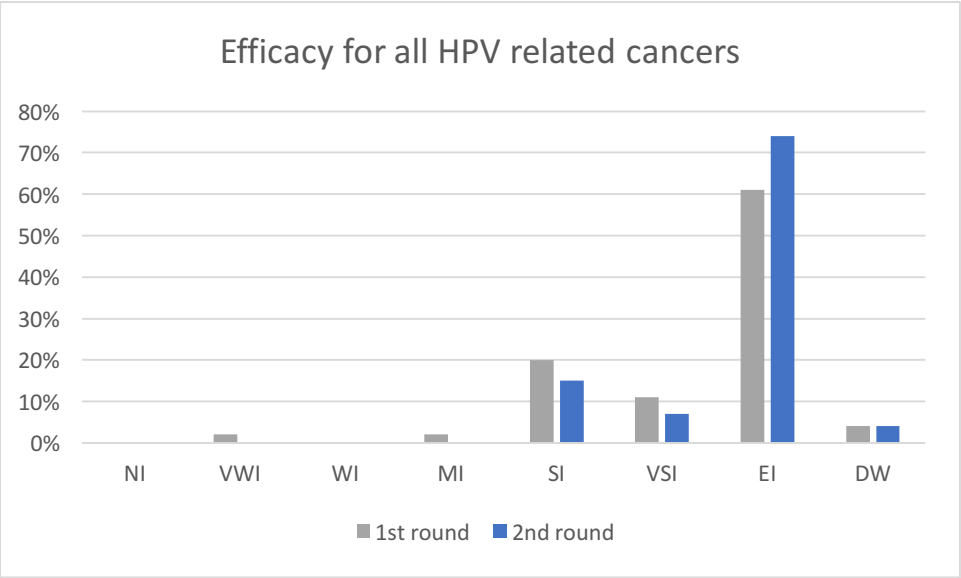

Figure 26. Comparing results for HPV related cancers.

Same thing happens for the efficacy for warts. In the second round this criterion also reaches the level of agreement of at least 51%. The rise of valuing it “extremely important” is quite important, from 48% in the first round to 74% in the second one.

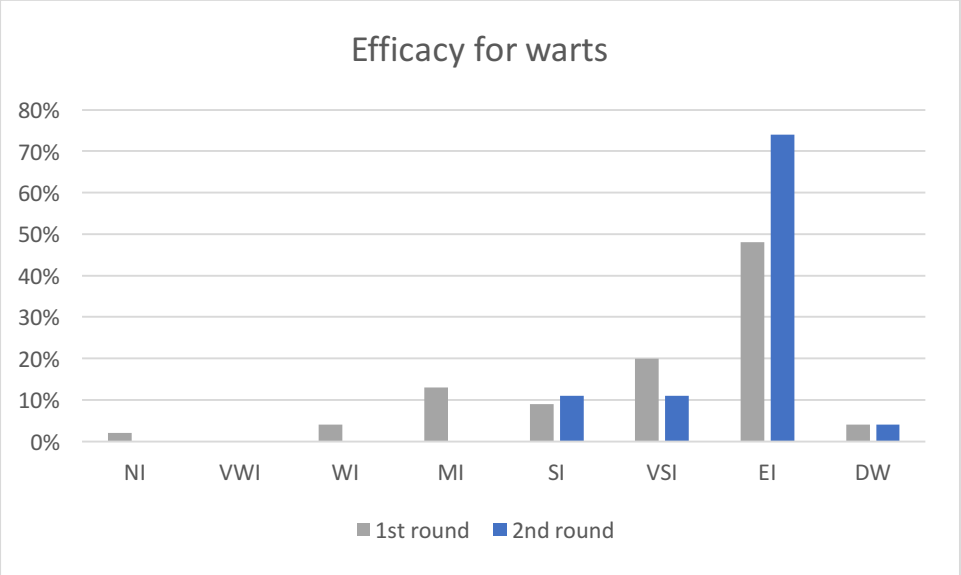

Figure 27. Comparing results for efficacy for warts.

The two criteria weighted in a more distributed way will be seen now.

For the side effects, it is seen an important topic but an agreement has not been reached.

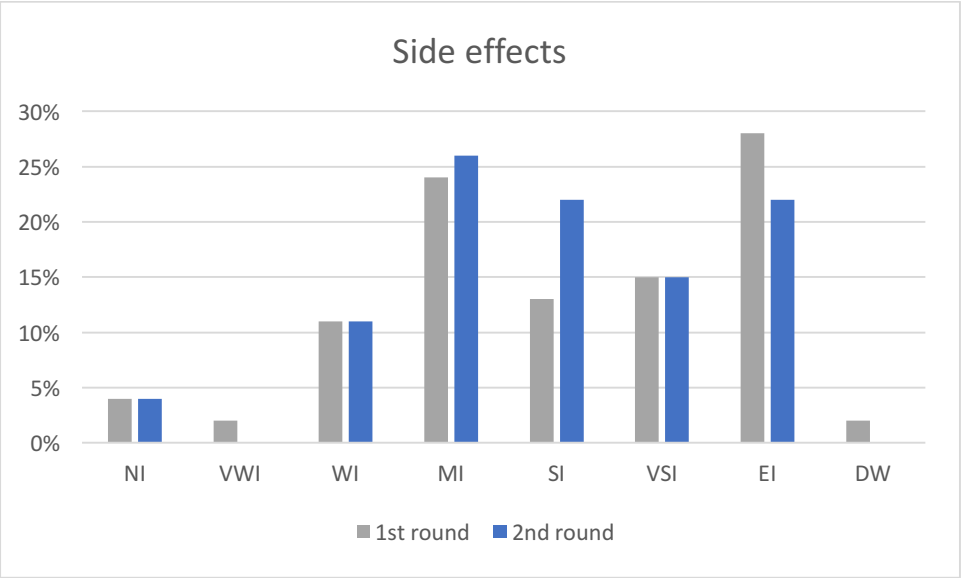

Figure 28. Comparing results for side effects.

Referring to time, the percentage is largely dispersed. It is considered less important than side effects, because the categories “extremely important” and “very strongly important” do not have a big percentage.

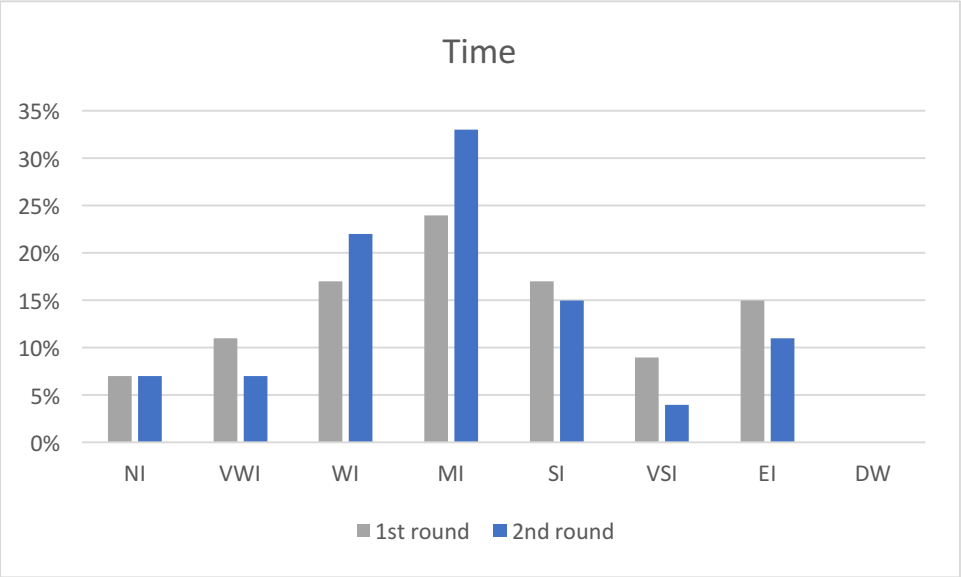

Figure 29. Comparing results for time.

To sum up, results say the agreement of at least 51% has not been reached for three criteria: cost, side effects and time. So, results are not conclusive. This means, that what has been done is not sufficient to build the model. That is what supposedly would be following done next. The following step would be to put in the model the ranking of the indicators to then assign weights. As the final weights for the criteria have not been assessed it cannot be done because which ones are more important wouldn't be known. They need to be important for the community and what the community wants regarding the weights is still not known.

Once analyzing the results, one possibility is to think that the ones that value poorly the efficacy maybe just disappeared in the second round and did not complete it. So, or they either changed the opinion or the ones who follow up the process were the ones for whom it was really important.

The results of the google form and the Welphi had not been correlated, but exists the chance to do it once the individual answers of the participants for the Welphi are requested. It should have been interested to carry out, for example, to state the hypothesis that homosexuals and bisexuals are more willing to get vaccinated. [89], [90]

It is feasible to think that probably, if the information about HPV was the first thing given they might have been more willing to participate.

Another group that was difficult to engage were the ones with issues with the vaccines. From all the answers of the google form, four of them do not believe in vaccines and other eight have fear of vaccines. Only one of the fear completed both rounds.

It is important to engage people and an action plan should exist to do that. Only 25% of all the participants invited completed the process. The fact of having so many different questionnaires facilitates the abandonment of the process. Having to register in a website to participate in the process has reported to be seen negatively. All these creates an environment where males have to be really interested to keep up all the steps. Ideally, it should be done in platform that manages it all and be spread through a link.

5. Conclusions and future work

The primary objective was to assist the community, communicating among themselves. It is possible to see that people changed their opinions, they had communicated, and, therefore, it is possible to see an evolution.
However, the results were more dispersed than what was expected. With this dispersion, it was not possible to see what the community thought. The medical doctors could not be informed about the thought of the community regarding the ultimate decision of being, or not, vaccinated but some clues can be provided.
It is more difficult to engage the ones with issues with the vaccines, as might be expected. The awareness of HPV in the male community is really low although the community also presented a high concern for being protected against the infection and regarding the cost of the vaccine, it is considered as one of the most important implications.
As one topic of discussion in the medical community is to weather introduce this vaccine in the vaccination plan for girls and boys [96] and cost, even without reaching a level of agreement had been considered for the community as an important factor, it is plausible to think that if the cost reduced, males would get vaccinated.

This was a preliminary study which goal was to explore the Delphi method in a way to engage a community in a shared decision context where the community can say something. The ideal, of course, would have been to see the model (the final decision) and then inform medical community. Given the potential and importance of this context, some future work suggestions are presented.

Eventually, there are two options to finish the model.
The first one is to conduct a third round of the process looking for a higher level of agreement. The level of agreement was not reached in the second round for all the implications, but it is possible to observe that there were implications on which the level of agreement was easier to reach than in others and a change in their opinions.

The other option is to, with this results in hand, seat in a decision conferring process in which this information will be used to inform a strategic group of students that will help to build the model. The opinions of the enlarged group would be taken into consideration and the strategic one would decide.

In both cases, it is important to raise the awareness of the community. This can be done in different ways. For example, a face to face session in the campus and invite a doctor.

One of these two options can be taken to finish the model. However, as said, it was not the main objective, which was to explore a new method.

Some of panelists stated that they could not express their real feelings and opinions while weighting the implications. The criteria asked in the Welphi platform were the implications of the vaccine. When assessing individually each one of the sentences that refer to each one of the criteria of the model, one can value all of them highly but the final decision might be not to take the vaccine, in concordance with his personal beliefs and opinions. Criteria have to enable to build a requisite model to represent all the situations and feelings. With this reason, the structuring part might need to be revised in order to include these criteria.
It is important to mention the fact that, as addressing a whole big unknown community not all of them would have the same values, which difficult the structuring of a model valid for everyone. As bigger the community is, this problematic also grows.

Given the high dispersion of results, it is very important not only to spread the questionnaire to have more people answering in order to understand why are the results so dispersed but also because in order to have robust information a larger participation is needed, which is translated into more data.

If this future work actually takes place, given the difficulties faced throughout the process: getting participants, engaging them and managing the different platforms where the information was (google form, Welphi, email…) it is very important for all the information to be in the same place and easily accessible. Ideally, the platform used should be able to manage everything, allowing for the Delphi process as well as for other questions. Having a link to disseminate the process would make it much easier, even more bearing in mind the community targeted, because university students make a lot of views in social networks.

As might be seen in the literature or shown in Figure 23, the population is not aware of this health issue so there is a lot to do in terms of public health to reach this people and make them understand the importance of the vaccine.

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